



## Chapter 9

# Black and Minority Ethnic Elderly: Perspectives on Long-Term Care

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*'Having crossed so many continents  
To settle in Glasgow,  
We still have time and energy left  
To develop the recommendations of your report.'*  
(A 91-year-old elder at the PRIAE-CRE Seminar)

## EXECUTIVE SUMMARY

### 1. Summary

The seminar findings reflect the patterns generated in research studies of the past 15 years. Progress in day care, housing and effective assessments for some in the post-community care era cannot be denied. For those unfamiliar with the subject, the expressions of elders and carers at the seminars may seem no different to those of white elders who also express dissatisfaction with social care, health service and housing. So where is the distinctiveness? The answer lies in the source of supply of care, the level of developments in care and a constant existence on the margins.

We analysed empirical studies in the 1980s and reached several conclusions, one of which concerned the centrality of minority ethnic organisations in the supply of care. We said then that assessing the evidence, such organisations were acting as 'primary providers' (substituting mainstream services) rather than acting as 'complimentary providers' to mainstream health, social and housing services (Patel 1990).

In the late 1990s, the Government's own inspection survey (Murray and Brown 1998), point to the inadequacies of mainstream providers and the compensatory effect of minority ethnic organisations who continue to act as 'primary providers' in the post-community care era. Given this *continuity* of mainstream neglect



and/or indifference, we can state that this constitutes *de facto* racism. In other words, the mainstream services *by default* are structuring the segmentation of care to minority ethnic elders into a long-term solution. Our concern here is not that the location of services are in BEM elder care centres. Rather that such location tends to be inadequately supported, maintained nor expanded.<sup>1</sup> This makes the development of comprehensive services and an ability to reach all sections of BEM elders (disabled, frail for example) problematic. Moreover, as Table 1 indicates, the current number of minority ethnic older people (i.e. 65+ years) stands at 3.7% or 4.2% of the ethnic minority population (depending on under-enumeration) with the increase to come in the approaching old age category (13.6% in the 45-64 years of age). The current lack of a foundation or low level of service developments will be dramatically felt in the next decade or two for the latter group as there will be a larger share of minority ethnic elderly population (1.3% currently of the 65+ compared to 4% of 45-64 years).

It is in this context that people at the seminar were vexed by the question of funding for care and alternative models of care: as they said they have already had to manage in the absence of both appropriate and effective mainstream provision.

We also need to emphasise the recurrent point in all the seminars concerning the heterogeneity of BEM<sup>2</sup> elder population. Like the elders from majority group, not all BEM elders require the range of services recommended nor face the issues of disadvantage, discrimination and experience effects of ageing to the same degree.

The recommendations are fully provided in the text in Section 3. For the purpose of the Executive summary, we have identified under each question a key recommendation which gives a 'theme' to those explained in detail in Section 3.

The delegates had emphasised the importance of the implementation of these recommendations by the Government via the Commission's Report since they felt:

*'we have had too much discussion,  
action is overdue.'*

## 2. Recommendations

### 2.1 The appropriateness of current models of care

- (a) Where mainstream services have effectively engaged with 'different needs', (re: changes in communication, design, planning, assessment, staffing and delivery where the definition of 'culturally appropriate' is broader than mere technical aspects), BEM elders, carers and professionals express satisfaction with choice and standard of care.
- (b) Where the local market of care is already characterised by BEM elder Centres, the direction, shape and take up of services is already mapped out. In the 1990s we have several examples of 'what works' in housing, health and social care concerning BEM elder care. There are also several areas that remain unexplored. The capacity and method of services provided by such centres need to be examined as part of investment strategies.



### ***Recommendation 1a***

BEM elder care centres should therefore be strengthened, expanded to meet growing demands and regarded as primary providers of care rather than as an alternative to the mainstream. Commissioning and Funding bodies need to seriously examine their knowledge base and act in a non-stereotypical way in support of this.

### ***Recommendation 1b***

Mainstream health, housing and social care organisations need to urgently examine (and consequently act upon) on why they continuously *appear* to have difficulties in effectively responding to BEM elders and their carers' *ordinary not special*, needs. If they continue with the present approach of 'ad hoc, patchy and piecemeal developments', they will by default, have structured BEM elder centres into segmented long-term care solution on marginal resources, endorsing *de facto* racism in a modern society as we approach the 21st century. BEM elders' settlement in concentrated areas present planners with less difficulty in implementing the proposals.

### ***Recommendation 1c***

The relevant Government departments need to urgently take a proactive approach to stimulate the necessary action to prevent the structuring of the above scenario which can have serious social and race relations policy implications.

## **2.2 Accessing Services**

The delegates spoke cogently about why in the 1990s it was so difficult to establish what was available, where and how to access basic information on services. Research studies which we have cited all point to lack of knowledge and information on social care, primary and secondary health services ('going beyond visits to the GP and the hospital') among BEM elders and carers.

### ***Recommendation 2a***

The 'hush-hush' system to information on services needs to now be vocalised with a planned strategy in marketing of services. Here good quality translated leaflets are only one part of the communication programme.

### ***Recommendation 2b***

Barriers relating to information, choice, culturally responsive care and underlying discriminatory processes which affect assessments need to be eliminated. The elders of tomorrow will demand an equal but perhaps different service and the authorities need to be prepared for this as well as be flexible in their approach to care.

## **2.3 Planning and Paying for Long-Term Care**

The question of affordability, ability and willingness to pay for care received a mix of reactions. There was a feeling that equitable treatment is easily dispensed with when it comes to payment but not so when receipt of effective care is called upon. Most delegates emphasised the context of employment, discrimination and disadvantage in the working period as well as sustained effects of long-term



unemployment. The continuation of this cycle for the elders of tomorrow was also expressed. The particular effect on specific minority ethnic older women and carers who have remained outside of the formal employment needs to be recognised. The research we have cited in Section 1 provide empirical evidence for such views.

**Recommendation 3a**

The following principle expressed by an 86-year-old elder was supported in all three seminars. That,

*‘those who have means must pay  
those who have no means must be provided for  
without hesitation nor humiliation.’*  
(Person Z)

It should be noted that the former sentence is relative: in the discussion it referred to those who ‘were very well off’! The emphasis was on generating economic independence and not structuring dependency on various sources, should care be required.

**Recommendation 3b**

Carers’ informal role should be recognised in monetary terms for the care they provide and the savings they generate for the state. Their improved income base may not only help them and the family but may contribute to greater economic independence in their own old age.

**2.4 Reducing Dependency: what alternative models of care are being considered currently for the future?**

The discussions and proposals can be grouped as those relating to:

- (i) personal ageing and well being;
- (ii) specific developments to promote healthy and independent ageing; and
- (iii) transfer learning and changing of roles.

**Recommendation 4a**

Support and strengthen the BEM elder Centre base, particularly day care. Elders can remain at home and yet activate social contact at the day centres. Initiate, fund and direct work aiming at healthy independent ageing, with positive mind and body in BEM elder Centres.

**Recommendation 4b**

New roles (e.g. volunteering, short-term employment) of elders should be encouraged to break social distance between the young and old, thereby creating a better view on the ‘value’ of older people in society.

***Recommendation 4c***

The new Parliamentary bodies in Wales, Scotland and Northern Ireland have an excellent opportunity to build in at the outset the arrangements which will support effective care and independent ageing for BEM elders and carers in collaboration with BEM elder bodies in each area.

**2.5 Future Model of Care*****Recommendation 5***

Mainstream authorities and funding bodies need to be guided to enact the elders' consistent recommendation in all three seminars – that the future model of care should attempt to cater for all minority ethnic groups 'under one roof', but still catering to specific person-centred requirements. This would enable the individual to receive culturally sensitive care and enable greater understanding between communities and foster good community and race relations.

We at PRIAE have termed this as the 'Pomegranate'<sup>3</sup> model exemplifying the principle of 'unity in diversity'.





## SECTION 1. INTRODUCTION

This report sets out the views and perspectives of black and minority ethnic elders, carers and managers concerning long-term care for the elderly. Based on these views, recommendations are made to the Royal Commission on Long-Term Care for the Elderly. The information is supplemented with a section on the general context of care for black and minority ethnic elders (Section 2). The purpose of this section is to provide an overview of the demographic, socio-economic and health context.

This is then followed in Section 3 by the core empirical part of this report, in which the views and experiences of selected elders, carers and managers of minority ethnic elders' organisations are considered. The findings were derived from a Seminar series managed jointly with the Commission for Racial Equality held in Leeds, London and Edinburgh between 2 and 11 September 1998. The findings are analysed further to set them within the context of relevant research studies. To this end particular reference is made to two recent reports, one from the Department of Health: *'They Look After Their Own, Don't They?'* assessing the current state of social care provision for black and minority ethnic elders and the second from CNEOPSA study: *'Dementia and Minority Ethnic Older People: managing care in the UK, Denmark and France'*.

Finally, this analysis allows us to make a number of critical recommendations in the final part of this report in Section 4. Appendix 1 provides the methodology employed to establish elders, carers and managers' views. Their views are presented in a 'raw' form as in Table 3.

## SECTION 2. THE GENERAL CONTEXT

### 2.1 Demographic trends

Everyone has ethnicity and an ethnic identity. The term 'ethnic minorities', 'minority ethnic groups', 'black people' etc. all generate some discussion and disagreement. In this report we use the broad terms 'black' and 'minority ethnic people', and use the shorthand terms 'minority ethnic' or 'minorities' to signify the fact that:

*'they are both relatively small in number and are in some way oppressed or subjected to inferior treatment on account of their ethnic or racial identity.'*

(Giddens, 1993, cited in Ratcliffe 1996, p. 4)

We also recognise that this broad terminology, divided into ten sub-categories for census collection in 1991:

*'conflates an enormous number of groups with quite distinct cultural, spatial and religious heritages; for example, a variety of northern European groups, including the indigenous British and, significantly, the Irish and those of Greek or Turkish origin (including Cypriots of both national origins).'*

(Ratcliffe, 1996, p. 5)

The 1991 Census for the first time determined ethnicity without resorting to 'country of birth', but it specifically omitted the category 'Irish' amid demands. This understanding contributed and determined the list of delegates invited to the three seminars.



A black and minority ethnic presence in the UK is not a recent phenomenon – with the Irish in the 16th, 17th and 18th centuries and the Jews, the Poles and other minority groups in the late 19th and 20th centuries – the migration of people from the Caribbean and Indian sub-continent mainly dates from the post-war period. According to the 1991 Census there were some 3.2 million minority ethnic people constituting some 5.5% of the total population in Great Britain. Their presence extends to most districts of Great Britain and Northern Ireland, making the UK a multi-ethnic society. The 1991 census however omitted ethnic classification in Northern Ireland. According to the Northern Ireland Council for Ethnic Minorities, there are estimated 26,000 people of whom (est.) 8,000 are Chinese with Indians, Travellers, African/Afro-Caribbean and Pakistani representing over 1,000 members each. We have no information on age groups for Northern Ireland and therefore there is an urgent need to undertake a survey of minority ethnic groups on characteristics and conditions to establish a base line for care planning in the future. Similarly for refugees and asylum seekers we experience difficulties in data. According to the Home Office information (1995), for example in 1995, there were over 75% of applicants under 35 years of age. However we are beginning to see in practice several groups emerging (Vietnamese, Somali, and Chilean Associations) who are also striving hard to establish care for their older members.

Table 1 shows the distribution of the population in Great Britain according to age and ethnicity. It shows the relative youth of the minority ethnic population compared to the white population and the diversity in patterns of ageing amongst different ethnic groups. Nevertheless, over 3% of minority ethnic people are in the over 65 years of age category compared to 16% of the white population. That is, of some total 8.8 million people aged 65+ years, 130,000 were from minority ethnic groups. In the 85+ age group, minority ethnic groups account for 3,871 people from a total population of 830,678.

If we consider the share that minority ethnic and white groups make of the total population in different age ranges, we find that minority ethnic groups make up 1.3% and 4% of the 65+ and 45-64 year age ranges, respectively, compared to 98.7% and 96% for the corresponding age ranges for white groups (Owen, 1996; Warnes, 1996). This means that in the next decade there will be an increased percentage of minority ethnic people reaching retirement age resulting in a considerable change in the present profile described above. This significant difference in the share of minority ethnic elders today and that of tomorrow is explained by patterns of migration, refugee arrivals, and settlement. So excepting communities who have had a long-established presence, those who arrived in the post-war period, 1950s and 1960s as young adults, are the elders of today: the 50th anniversary of Windrush for those arriving from the Caribbean for example also mark this age progression.

Moreover, there are variations in the ageing profile in minority ethnic groups depending upon location and gender, with:

*‘ . . . females more numerous but the sex ratio of 1.006% was slight in comparison to the ratio of 1.069 in the white population.’*  
(Warnes, 1996, p. 161).

There are variations between ethnic groups so for example, men outnumber women particularly among Bangladeshi and Pakistani groups.



Table 1: Age breakdown of ethnic groups in Great Britain, 1991  
(Note: based on data adjusted for Census under-enumeration)

Ethnic Group	Total population	Percentage of total population					
		Age 0-4	Age 5-15	Age 16-24	Age 25-44	Age 45-64	Age 65+
<b>White</b>	52,893.90	6.5	13	12.9	29.3	19.2	19.3
<b>Ethnic minority groups</b>	3,117.0	11.1	21.7	16.4	32.9	13.6	4.2
<b>Black</b>	<b>925.5</b>	<b>11.1</b>	<b>18</b>	<b>16.5</b>	<b>33.8</b>	<b>15.4</b>	<b>5.1</b>
Caribbean	517.1	7.6	14.1	15.3	33.4	21.8	7.7
African	221.9	11.8	17.1	17	42.7	9.5	1.8
Other	186.4	20.1	29.6	19.3	24.6	4.4	1.6
<b>South Asian</b>	<b>1,524.30</b>	<b>10.9</b>	<b>24.6</b>	<b>16.5</b>	<b>30.5</b>	<b>13.5</b>	<b>3.9</b>
Indian	865.5	8.9	20.5	15.5	34.9	14.9	5.2
Pakistani	491.0	13.2	29.2	17.9	26.1	11.3	2.4
Bangladeshi	167.8	15.1	31.9	17.9	20.8	12.7	1.5
<b>Chinese and other</b>	<b>667.2</b>	<b>11.6</b>	<b>20.1</b>	<b>16.1</b>	<b>36.9</b>	<b>11.4</b>	<b>3.8</b>
Chinese	162.4	7.1	16	18.4	41.4	12.7	4.4
Other – Asians	204.3	8	16.2	15.1	43.6	13.7	3.1
Other – Other	300.5	16.4	25	15.5	29.9	9.2	3.9
<b>Entire population</b>	<b>55,969.20</b>	<b>6.7</b>	<b>13.5</b>	<b>13.1</b>	<b>29.5</b>	<b>18.9</b>	<b>18.5</b>

Source: Owen, D. 1996, p. 116

Table 2 indicates the spread of elders from different communities

Table 2: Age breakdown of ethnic groups in selected areas of Great Britain, 1991  
(65+ for England and 60+ for Scotland as a percentage)

Local authority area	White	Black	Asian	Other
<b>England</b>				
Hackney	89.4	7.5	2.1	0.9
Hounslow	93.3	0.6	5.6	0.6
Birmingham	95.3	2.0	2.6	0.2
Manchester	97.4	1.6	0.9	0.2
Walsall	97.9	0.5	1.6	-
Kirklees	98.4	0.5	1.1	-
Bolton	98.5	0.2	1.2	0.1
Nottinghamshire	99.1	0.2	0.7	-
<b>Scotland</b>	<b>20.9</b>			
■ Chinese	4.6			
■ Pakistani	2.8			
■ Indian	5.6			

Source: OPCS: Census, 1991



## 2.2 The socio-economic position

The diversity in age distribution, location concentrations – 97% of all minority ethnic groups reside in England of whom some 45% live in Greater London; 2% and 1.4% live in Scotland and Wales respectively (Owen, 1996) – and gender differences, reflect the pattern of migration and settlement. This process has also determined the social and economic position of today's minority ethnic elders. Their social and health care needs cannot be understood without reference to their experience of employment, housing and income.

The early surveys from the Policy Studies Institute (1977; 1984) explained the unequal distribution of minority ethnic workers in the 1970s and 1980s (i.e. the elders of today) by sector and industry, as being due to differences in labour requirements between various industries and discrimination by employers and unions. Once in jobs, discrimination in earnings followed suit. The disparity in earnings as regards 'working period' as well as the length of working life, coupled with known under-claiming of welfare benefits, account for differences in pensionable income (Askham *et al.*, 1995).

For the emerging generation of elders we must add the effects of long-term unemployment, characterised by the decline of the manufacturing base (foundries, textiles, transport) where many ethnic minorities had been concentrated. These factors may contribute to the use of services in many centres by minority ethnic elders beginning from the age of 55 years. This has serious implications for policy since there may be 'early ageing' amongst this group.

In the 1990s the concentration of employment has been in four sectors: Manufacturing; Wholesale, retail; Real estate, business activities; and Health and Social Work.

The unemployment rate experienced by 16-59/64 age groups was more than double the rate for white people, for both women and men. The CRE Factsheet (1998) reports that 35% of economically active 16-24 year-old black people were unemployed in spring 1997 compared with 13% of young white people. For refugees the figures can be as high as 80%. As for earnings, those from minority ethnic groups received 92% (average hourly, full-time) compared to white employees.

On average, earnings between white and minority ethnic women were the same except for Pakistani and Bangladeshi women (PSI Survey 1997, Labour force Survey, 1995-1996). The effect of low income for particular minority ethnic older women and carers who have remained outside of the formal paid employment carry implications regarding savings and pensionable income (Patel 1990, Netto 1996, Modood *et al.*, 1997). We must also add the distribution of self-employment where for Chinese and Pakistanis, it is almost double that of white group. It has been long recognised that self-employment particularly in small-scale businesses (shopkeepers) conceals the under-employment within the family with reduced net income for the household. Although we must recognise the mobility of some minority ethnic groups as illustrated by the latest PSI report(1997), on the whole such figures indicate a broad picture of inequity in employment and earnings for the emerging generation of elders.



As for household composition, 1 in 6 Indian households is a three-generation one compared to 1 in 40 for white groups. Regarding single parent families with dependent children, 32% of black families belonged to this group compared to 8% of white families. The 1991 Census and PSI Survey (1997) indicate variation in housing ownership among minority ethnic groups: 80% among Indian and Pakistanis compared to 45% for Bangladeshis. At the same time it is recognised that the type of housing owned and its concentration in urban areas determine its low realisable value. Such composition of families and ownership of housing stock point to considerations in the future on whether a large section of the minority groups can afford to plan and/or translate their current assets to future stream of earnings for care in their old age.

Minority ethnic elders face a range of health problems, and mainstream health and social services have been inadequate in meeting their needs in England, Scotland and Wales as various studies show (Bhalla & Blakemore, 1981; Farrah, 1986; Patel 1990; The GOAL Project 1994; Pharoah, 1995; Askham *et al.*, 1995; Lindsay *et al.*, 1997; Bowes and Dar 1997, Patel, Mirza *et al.*, 1998; Murray and Brown, 1998). Some of these studies also show evidence for a relatively higher frequency of using health services, including general practitioners (GPs) by elderly Afro-Caribbean and Asians compared to white groups. However, frequency of contact with GPs and hospitals does not necessarily reflect the quality of treatment received.

The latest Murray and Brown Survey (DH 1998) provide us with good information on policies, strategies and practice in the care of black elders by social services departments. This survey adds to the empirical studies conducted in the last 18 years. For health we have considerably less information, although the CNEOPSA study (1998) presents epidemiological data on dementia and a summary of the health profile of black elders from various surveys; the Askham *et al.*, (1995) and Pharoah studies (1995 at ACIOG) provide a good range of information on the responsiveness of health professionals to care 'appropriately'. As for studies on carers of older people (Patel *et al.*, 1998, Katbamna *et al.*, 1998, Netto 1996) all point to a 'mirroring effect' to issues outlined for black elders: low income and support, lack of knowledge on services and benefits, culturally and linguistically inappropriate services and lack of recognition by health, housing and social care to work with diverse needs of carers and their elders.

Under the NHS Ethnic Health Unit there were several practice-based projects supported which would be useful for us to consider. However in the field of black elder health care, there is an agreement that health lags behind social services particularly in professional training and 'effective' care practice.

These experiences need to be set within the context of the known prevalence of individual and institutional racism in the economy as studies from each decade have confirmed (e.g. PSI Surveys). The forces of discrimination contribute to explaining the division and segmentation in the labour market which the elders of today experience as a disparity in earnings (and consequently also current pensionable income), and as barriers and/or a lack of responsiveness to service needs when trying to access social and health care services.

The 1991 census data allow us to comment on remittances sent by minorities: all these effects result in a net lower current income with a lower savings ratio than



might otherwise be the case. The DSS data on distribution of disposable income, 1994-95, confirm that generally (although there are variations between the minority groups) there is an over-representation of minority groups in low income households – with Pakistanis or Bangladeshi households occupying the bottom quintile. This accords with work Dr. Evandrou has conducted at King's Fund using GHS data over ten years.

### **The Future**

The crucial point here is that when we add the experience of unemployment and existing lower income in households, this means that the future generation of older people from minority groups may well show similar characteristics. The 1991 Census analysis and PSI Fourth Survey (Modood *et al.*, 1997) speak of economic mobility for some groups but the issue of convergence is not clear: i.e. minorities closely approximate trends in majority groups rather than the margins.

An elder's comment summarises aptly what would enhance her quality of life in old age. When asked what her main wish was currently, the response was 'can you arrange for the bills to stop coming in'.

Such a comment may seem no different to that of many elders in general. However, it is the cumulative disadvantage of effects over time due to structural forces and evidence of systematic discrimination in our society that put black and minority ethnic elders' (and many elders of tomorrow) in such a precarious economic position.

## **SECTION 3. AN EXPLANATION OF THE SEMINAR RESULTS**

### **3.1 Introduction**

We have given the detailed findings of our report below in Table 3, Appendix 1. The tabular form was preferred because it allowed the full range of issues, experiences and recommendations from elders, carers and managers to be expressed in a 'raw' form. In other forms we would have lost the impact of our findings and defeated the purpose of the seminars. However, what cannot be conveyed in a 'raw' form is:

- (i) the level of concern amongst our delegates;
- (ii) the degree of insight they have from their experience of ageing/or working in the area; and
- (iii) the ability through text to actually perceive the warmth and feeling of well being (i.e. atmosphere) in day centres with particular organisational culture.

We have to consider these points against the backdrop of their struggle for survival and resources in trying to maintain some services. Although 'atmosphere' may be an elusive term, it is precisely this that the delegates projected at the seminars particularly in complimenting the organisers for actually holding the seminars. This reference to 'atmosphere' is also made in the report concerning elders in Wales (GOAL Project). In Northern Ireland a specific service to minority ethnic elders does not currently exist. The view of the Northern Ireland Council for



Ethnic Minorities was that work needed to begin now since minority groups would reach old age in the very near future. Added to this was the urgency for data survey on the characteristics and circumstances of minority groups since Census 1991 omitted asking questions on ethnicity in Northern Ireland. This is a perfect opportunity to 'build-in' initiatives on minority issues as the peace process in itself will generate new developments.

We also need to emphasise the recurrent point in all the seminars concerning the heterogeneity of BEM<sup>4</sup> elder population. Like the elders from majority group, not all BEM elders require the range of services recommended nor face the issues of disadvantage, discrimination and experience effects of ageing to the same degree.

Below is an analysis of our findings using the four questions we put to Elders, Carers and Managers as sub-headings (see Methods in Appendix 1).

## 3.2 The appropriateness of current models of care

### 3.2.1 Views on mainstream health, social care, housing providers

All three groups – elders, carers and managers – said that services which they were aware of were used, but were not necessarily 'BEM-friendly'. While delegates appreciated the general issue of scarcity of resources in all three sectors, there was a marked observation that historically there have been difficulties in recognition of the needs of BEM, in service design, planning, assessment and delivery. Over time the reduction in such difficulties have not been overcome.

- (a) Inadequate mainstream care was expressed as a lack of supply (as measured by the range and choice of services), and as culturally inappropriate care (as measured by the quality of care). Both these shortcomings covered basic *ordinary* daily care requirements such as physical care, food, and ability to exercise religious/spiritual beliefs and communication. There was also the serious issue of stereotypical assumptions and attitudes regarding where care may be provided – e.g. the myth of 'they look after their own'.
- (b) Lack of supply concerned two groups in particular: elders with refugee status (e.g. Vietnamese) and several BEM groups who were in one region but were both small and dispersed (e.g. Fife in Scotland). For these groups the lack of supply was more poignant since there were no specific minority-led services for elders. They emphasised that well before debates on quality of care were discussed, the issue of supply needed to be addressed urgently.
- (c) Inadequate care added more stress for the carers when considering the desirability of mainstream care for personal needs. Inadequate care accentuated the 'personal guilt' felt by them.
- (d) A recurring theme was that *when* mainstream providers were engaged with a 'different needs' agenda, BEM elders and carers were satisfied with the choice and standard of care given. Examples were cited of residential and day care services for different BEM elders housed under one roof, but designed in such a way as to ensure that their cultural needs were met by employing staff from different communities. In health, multicultural teams worked with BEM elders at centres to extend health services and to develop alternative models.



However, there were two main weaknesses cited:

- the scale of such provision was inadequate and the confidence amongst elders in accessing these provisions was low;
- satisfaction rates were qualified by managers – the path to attaining such progress is not straightforward and there is a cyclical pattern in registering the need for culturally appropriate care: for each minority group similar cultural and communication issues arise requiring separate cases to be made. However, this is inefficient and ineffective for the communities, the authorities concerned and in terms of the net effect it has on the elders and their carers.

(e) The above explanation, sadly, sits comfortably with the research findings cited in the Introduction and General Context section above. The latest DoH report by Murray and Brown, *'They look after their own, don't they'* (1998) point to the range of good practice examples by Social Services Departments. These span policy and planning, information and communication, assessment and care management and service delivery. That progress is being made cannot be denied. But the gap between those authorities who have made this progress and those who have yet to start is not bridged. These gaps were clearly highlighted in the recent CNEOPSA study: *'Dementia and Minority Ethnic Older People'* (Patel, Mirza *et al.*, 1998).

So service development in the mainstream is still regarded as patchy and inadequate, and the same is true of areas like dementia and elder abuse. In the area ethnic minority elders suffering from dementia, eminent people/leading organisations in the mainstream have, with one or two exceptions, omitted the target group in research, policy and development of care tools areas. CNEOPSA, a project within PRIAE, is working with the Stirling Dementia Development Centre, with the ADS, Alzheimer's Concern Ealing and some BEM Centres on care product developments to address the gaps in this area. Likewise on the issue of Elder Abuse a similar pattern of collaboration and work is being pursued. It is such start-up developments in neglected areas, which can make a difference at both policy and practice levels. The delegates at the three seminars registered their support for PRIAE's establishment.

(f) Elder groups emphasised in particular the changing patterns amongst young people in their communities. They did not see culture as 'static' and expected greater demands on authorities in the future, recommending that authorities needed to generate equality based solutions in care for the future. There was disagreement amongst the elders on whether tomorrow's elders would approximate today's majority cultural patterns. For example would there be a continuing need for interpreting and translation facilities?

## The Future

Our view is that for future old age groups there will be similar care needs but to a more variable degree: the level of 'mixing' and mobility is not equal among different ethnic groups. We know which groups face severe disadvantage, that over 40% are mixed marriages and that despite greater house ownership in some



communities, shifts in family values may throw up an even greater need for professional care as opposed to less.

In addition there is the issue of 'early ageing' amongst BEMs – in some policy and practice circles this is now accepted as fact. However the elders' views on 'reducing dependency' question below should give us some hope: that with concentrated and planned efforts, despite the economic and social hardships which individuals may face, the attitude to early ageing should be shifted rather than accepted.

### 3.2.2 Views on black and minority ethnic elders' organisations

- (a) It could be argued that since the elders and carers at the seminars came from BEM elder organisations they have an interest in promoting themselves. However studies on minority ethnic elders'/community care by Patel (1990), Atkin (1993), Askham *et al.*, (1993), The Goal Project (1994), Butt (1996), Bowes and Dar (1997), Patel, Mirza *et al.*, (1998) and Murray and Brown (1998) all point to the critical fact that such organisations
- (i) make BEM elders' issues visible, and
  - (ii) that they meet their basic needs in the absence of an adequate response from mainstream providers.
- (b) Given the role played by BEM Centres, elders and carers in our seminars took for granted the relevance and significance of such organisations as a 'substitute' provider of services. Thus, they often spoke about such Centres requiring better funding sources and mechanisms, long-term support and an expansion of the range of services that they presently provided (day care, sheltered/housing). Implicit in their view then is that they see the *source of supply* of social care coming from BEM Centres, irrespective of mainstream funding arrangements.
- (c) BEM elder Centres are meeting basic needs in most cases, innovating in some areas and attempting to shift priorities to meet growing demands. They also act a 'bridge' between mainstream providers and BEM elders and carers, advocating on their behalf. Their significant strength lies in the fact that they deal with multi-agencies in response to the needs of elders and carers – in essence co-ordinating services. Many of these Centres were/are pioneered by today's elders and this is reflected in the appropriateness of what is available and how best it is delivered – again raising the point of organisational culture discussed above.
- (d) The weakness of BEM Centres lies in the role they have taken as primary providers of care, when considered within the historical context of temporary, low level funding, with poor infrastructure and a funding system determining the services they provide. All three groups emphasised the growing gap between the demands of BEM elders and carers, and the supply of staff (with temporary funding). For example, in one London Borough the Chinese Community Centre had two part-time workers who met *all* the demands of Chinese elders and carers. As new groups of elders emerge in the locality, the funding source meets additional competition.



- Regarding determination of services, as Patel (1990) and Murray (1998) speaking at the seminar commented, BEM elder services have been ‘inserted’ into a standardised mainstream concept without much room for experimentation. The pattern has been established and within that, minorities have made adjustments in *how* the services are delivered rather than examining the entire constitution of the services *per se*.
  - It is our view that the funding system from both mainstream and charitable organisations have locked the BEM elder Centres into continuing with this practice: delegates spoke of applications being rejected if it was a ‘novel’ idea trying to meet certain aims by experimenting with different care approaches. This is also PRIAE’s experience and it suggests that such bodies have formulated a view of what it is that BEM elders require. Unless there is a break in this tradition, we see the future of care as being determined by funding criteria rather than meeting the diverse needs of BEM elders and carers.
  - Notwithstanding the above, views were also expressed about improvements in the BEM elder Centres to promote activity and ‘intellectual refreshment’.
- (e) Our findings therefore highlight a significant difference in the receipt of care between white elders (predominantly relying upon mainstream services with complementary services from the voluntary sector) and minority ethnic elders (predominantly relying upon BEM elder Centres located in the voluntary sector with or without funding from the mainstream, as secondary providers).

The *source of supply* of care is therefore different, and historically the funding base is clearly different. It is generally accepted that the different evolution of BEM elder Centres is the result of ineffective care being provided by the mainstream. It has been a response rather than a desire to be ‘separate’. This point was raised by some elders and may partly explain their recommendation in all three seminars that the future model of care should cater for all minority ethnic elders ‘under one roof’, but maintaining person-centred care to reflect diversity.

### 3.3 Accessing services: the experiences of carers, elders, and managers engaging and co-ordinating services with social services, health and housing

- (a) All three groups emphasised the issue of limited choice, poor information, cultural and language barriers and the underlying presence of discrimination as key factors in accessing services effectively. This was further compounded by BEM elder Centres being unable to facilitate access for all cases since they themselves are under immense pressure to deliver services ‘on the ground’.
- (b) Where housing services are accessed and are culturally appropriate, the very nature of making them culturally appropriate is creating a higher price differential due to increased costs of imported daily raw materials. The higher price differential is then the deciding factor for locating BEM elders in a white elder centre rather than one which may be more desirable by the elder and which is culturally appropriate.



- (c) The general experience of excess supply in residential care is not a feature for BEM housing associations. Indeed it is the reverse.
- (d) There are serious concerns expressed regarding hospital discharge. Rehabilitation work is patchy and in many cases absent. In one seminar a 75-year-old through an interpreter described the following: he had spent five weeks in a hospital and his wife whom he had cared for died soon after. During the five weeks, the hospital made no arrangements to explain his condition nor the treatment he would receive as a result of their diagnosis; the council housing repairs were simply not done despite appointments extending to two years and no assessment had taken place by the social services department. A local community centre had arranged for this elder to receive one hour of home care per week through its volunteering scheme.

Following PRIAE's notification of this case to the relevant SSD, at the time of writing this report, it received an immediate and an encouraging response that the elder's case would be urgently assessed. Within less than a month appropriate action had been taken by the SSD. Although we were pleased with the outcome it adds to our overall concern that as long as such elders are 'slipping through' the normal assessment processes, external intervention – and perhaps the presence of a body like the Royal Commission – is required to ensure that 'normal' processes are carried out.

- (e) Efforts by organisations to translate leaflets and employ interpreters were positively regarded but with a qualification: translations need to communicate (similar to Basic English Campaign) rather than pass 'literary tests' and should not be the sole method of communication. Interpreters are in critical positions and their role needs to be urgently re-examined.
- (f) The 'hush-hush' system of information: there was common agreement on this view expressed by an elder, Mr. X. There is a general belief particularly among the elders that services designed for them are not in the interest of the authorities to voice, highlight or communicate about. If this were the case, resources would not be able to keep up with demand and expectations.

Viewed from this point of view, we would suggest that the current barriers to information, access to services and inappropriate care is effectively dampening demand from BEM elders. Consequently, this is a saving and frees resources for use elsewhere. This is in stark contrast to some carers who expressed discriminatory comments from white neighbours when aids were delivered at home – e.g. 'they get everything'.

### 3.4 Planning and Paying for long-term Care

- (a) This area is explained first in the context of the previous two questions and second on the principles of care and its payment. Regarding the former, the following summarises the experience of inequity:

*'Paying Taxes I'm treated as an English person;  
Getting services I'm treated as an Asian.'*

- (b) Similarly there was some confusion that on the whole, NHS services were free while charging was operational for social care. Lack of uniformity in charging policy was most vocalised in Scotland.



- (c) As to asset holding, it was recognised that among some BEM groups there was greater owner occupancy households. It was also recognised that in many of these cases households were multi-generational and that it was unlikely that the elder commanded a share, having already distributed it among family members. This made assessments difficult and when required to pay for care family conflict ensued and in some cases led to elder abuse.
- (d) Disadvantage, discrimination and segmentation in the labour market have tied many BEM elders to a position of low income. This recognition was expressed most clearly in, 'I can't pay my bills now, how else am I going to pay for care when I need it' – by an elder at one of the seminars. A lack of knowledge on what benefits individuals were entitled to aggravates the situation further.
- (e) Recognition was also given to the culturally specific pattern of redistributing one's income to family back home. Remittances were regularly sent back thus reducing current income. If carers were involved, the lack of extra income in the household clearly reduced current disposable income as well as the potential for larger remittances.

We comment on this in Section 2, general context.

- (f) The introduction of large-scale payment would be counter-productive according to the elders group: first at a personal level, during one's working age it would cause a disincentive to work hard and save as a planning method for old age. This in turn may generate various dependencies.

Second, introduction of a full pricing policy would dissuade elders from visiting day centres etc. Lack of demand may spur multiplier effects in BEM communities which already have high unemployment. It is not the best recipe for encouraging active ageing. Third a very strong feeling articulated by elders was that they have already paid into the system with an expectation that this had a purpose: to contribute to their well-being in old age.

The findings here give support to the preliminary analysis conducted at PRIAE's request by Clarke (1998) from the larger research study on attitudes towards funding and provision of care in old age (Parker, NCCSU). It was found that the significant difference between white and BEM sub-samples concerned the issue of long-term care Insurance (LTCI). BEM respondents showed a greater propensity (including younger members) to oppose such a cover

- (g) To seek additional sources of finance: the very rich in the community should be encouraged to show greater generosity to BEM Centres since the 'community should contribute to looking after its own elders'.

### **3.5 Reducing Dependency: what alternative models of care are being considered currently for the future?**

- (a) The responses to this question can be classified as those belonging to
  - (i) personal ageing and well being,



- (ii) specific developments to promote healthy and independent ageing, and
  - (iii) transfer learning and changing of roles.
- (b) On personal ageing, delegates explained that there needed to be a complete re-think on the entire attitude towards work and life. Family carers also needed to plan for their old age at an earlier stage in their lives. ‘Thinking positively towards maturing to old age’ appeared to be the guiding principle, together with an emphasis on the need to be active physically and mentally once old. Cultural imperatives enforced a change in roles rather than dependency, but with changes in family structures the relationship was under considerable stress within family units.

The wish to plan for old age and be less dependent on the state was an issue for some when discrimination in jobs made a secure financial base precarious. There was also concern about the level of racism in society (one elder spoke about prisons, mental health and young black men; for another elder, an older brother from India was denied entry into Britain to join in celebrating their Golden Anniversary). This added to their insecurity, concerns and attitude towards life as they age in Britain, irrespective of whether they experience racism directly.

- (c) On specific developments there was an overall view that the struggle to establish what services they currently have made the task of considering alternative models more difficult.
- (d) There is much to learn from elders and for them to learn amongst themselves, as well as across generations. A climate that fosters this was seen as increasing active ageing and thus altering the role elders may have in a future information society. The wish to be IT literate and continue to be flexible individuals was seen as something to be supported.

## SECTION 4. SUMMARY AND RECOMMENDATIONS

### 4.1 Summary

The seminar findings reflect the patterns generated in research studies of the past 15 years. Progress in day care, housing and effective assessments for some in the post-community care era cannot be denied. For those unfamiliar with the subject, the expressions of elders and carers at the seminars may seem no different to those of white elders who also express dissatisfaction with social care, health service and housing. So where is the distinctiveness?

The answer lies in the source of supply of care, the level of developments in care and a constant existence on the margins: for example, dementia is regarded as a marginal area and the submission by the Alzheimer’s Disease Society to the Royal Commission reflects the severity of the problem at policy, practice and resource levels. Appreciating this, the issue of dementia and minority ethnic older people occupies a sub-marginal space at the same levels. Moreover as Table 1 indicates, the current number of minority ethnic older people (i.e. 65+ years) stands at 3.7% or 4.2% of the ethnic minority population (depending on under-enumeration)



with the increase to come in the approaching old age category (13.6% in the 45-64 years of age).

The current lack of a foundation or low level of service developments will be dramatically felt in the next decade or two for the latter group as there will be a larger share of minority ethnic elderly population (1.3% currently of the 65+ compared to 4% of 45-64 years).

At a research and knowledge building level, we have yet to generate good understanding on models of ageing, approaches to care, theory building in staff-elder relations, carer-elder relations etc. In 1998 we had the first book on dementia for the target group published (CNEOPSA study). This indicated the level of investment required in this growing area.

And yet in the mainstream the movement to respond effectively in services has been patchy for over two decades: examining services in 1980-1990 (Patel, 1990) and later through the Social Services Inspectorate's Survey (Murray and Brown, 1998). We characterised this situation in our background paper as:

*'However, reading the vast recommendations one can reach the conclusion that some authorities are making good progress, while others are slow and some are not doing anything at all.'*

It is in this context that people at the seminar were vexed by the question of funding for care and alternative models of care: as they said they have already had to manage in the absence of both appropriate and effective mainstream provision.

Seminars did not take place in Wales and Northern Ireland. However, for Wales the GOAL Project report on BEM elders (1994) highlighted similar experiences in the management of care. The added dimension to this would be the issues and agendas generated as a result of Welsh Language and Identity. It is therefore recommended that specific work around the four questions which we have rehearsed here are applied to both Wales and Northern Ireland.

The following recommendations were made by the elders, carers and managers at the three seminars and/or are derived from their substantive comments. Each set of recommendations is given under the four question headings that generated the data from these seminars. They cover how services are currently organised, delivered and paid for. The delegates had emphasised the importance of the implementation of these recommendations by the Government via the Commission's Report since they felt:

*'we have had too much discussion, action is overdue.'*

## 4.2 Recommendations

### 4.2.1 The appropriateness of current models of care

- (a) For mainstream services to be used, changes in communication, design, planning, assessment, staffing and delivery need to be made to make them culturally appropriate and relevant (the definition of 'culturally appropriate' is



broader than mere technical aspects being addressed: the inculcation of particular organisational culture which generates ‘presence of life’ with warmth and respect rather than ‘waiting to die feeling’ are equally important and determine the use and acceptance of services). The changes should also include participation of BEM elders and carers in design and delivery of services.

- (b) Where the local market of care is already characterised by BEM elder Centres, the direction, shape and take up of services is already mapped out. Such Centres should therefore be strengthened, expanded to meet growing demands and regarded as primary providers of care rather than as an alternative to the mainstream. Commissioning and Funding bodies need to seriously examine their knowledge base and act in a non-stereotypical way in support of this.
- (c) Lack of supply of appropriate care in some areas (e.g. Fife in Scotland) where ‘nothing exists’ needs to be urgently addressed. The model of care proposed is of an inclusive approach catering to several BEM elders under one scheme.
- (d) Day centres need to be supported, developed and enlarged since they are the main loci for BEM elders to access services and receive care. For social care and health and benefits agencies, such centres should be used as key channels of communication.
- (e) Housing demand needs to be urgently mapped since for some communities, no provision exists and where it does the demand outstrips supply.
- (f) Carers want appropriate and qualified professional staff in supporting their caring duties. Increase in respite care facilities is now urgent.
- (g) Specialist and competent staff are required for which current training deficits need to be addressed.
- (h) Employment of BEM personnel to reflect the local population should be the approach in stimulating training, experience and expectations so that a ready qualified pool exists to manage care.

#### **4.2.2 Accessing Services**

- (a) The ‘hush-hush’ system to information on services needs to now be vocalised with a planned strategy in marketing of services. Here good quality translated leaflets are only one part of the communication programme.
- (b) Barriers relating to information, choice, culturally responsive care and underlying discriminatory processes which affect assessments need to be eliminated. The elders of tomorrow will demand an equal but perhaps different service and the authorities need to be prepared for this as well as be flexible in their approach to care.
- (c) Person-centred care should by its very definition be culturally appropriate. BEM elder Housing Associations need to be recognised for delivering such care with the consequence of added costs. The standard pricing allocation needs to



adjust for this, otherwise culturally appropriate care will sink to its lowest denominator and therefore defeat the object of meeting the same needs differently.

- (d) Rehabilitation work needs to be done urgently in association with BEM elder Centres. It remains to be seen how far the current programme of Rehabilitation Work by the Audit Commission and King's Fund addresses this target group.
- (e) The practice of Primary Care Groups (PCG) should improve access since BEM elders have a higher frequency of visits to their GPs. However PCGs need to be specially trained to respond better to older people, people with dementia and their carers and in a culturally sensitive manner, irrespective of the PCG's background.
- (f) Access should not be limited to considerations in social, health and housing care. There should be pro-age policy in rail travel as it is for buses, and the limits on time should be revised: 'elders are part of society and should not hide away because it is 4 p.m.'. Such practice would have multiplier effects in strengthening a better social mix between generations, encourage active ageing among the old and 'allow BEM elders to see the country' which may affect race relations.
- (g) Experimentation to improve access needs to be encouraged with models like a 'one stop-shop'; there needs to be an outreach approach to consultation – e.g. Age Link Line and Road shows.
- (h) Support should be given to Joint Finance Initiatives but their method needs to be re-examined: currently this is time-consuming and can marginalise BEM elder Centres.
- (i) Cost-effective/Best-Value need a historical accounting system to ensure that BEM elder centres are not ruled out of the market or subsumed under a larger host with a different community base.

#### **4.2.3 Planning and Paying for long-term Care**

- (a) The following principle expressed by an 86-year-old elder was supported in all three seminars. That,

*'those who have means must pay;  
those who have no means must be provided for without hesitation nor humiliation'*  
(Person Z)

It should be noted that the former sentence is relative: in the discussion it referred to those who 'were very well off!' The emphasis was on generating economic independence and not structuring dependency on various sources, should care be required.

- (b) Paying for care should also not be accepted since it will act as a disincentive to hard work and financial prudence in working life.



- (c) Carers' informal role should be recognised in monetary terms for the care they provide and the savings they generate for the state. Their improved income base may not only help them and the family but may contribute to greater economic independence in their own old age.
- (d) The socio-economic basis for current low pensionable income should be taken into consideration when assessments are made – they must be free from racial discrimination. Cultural aspects of redistribution of income and joint or non-asset holding – i.e. high numbers of non-working BEM women and the higher concentration of self-employed in certain communities – need to be added to the overall understanding of financial capabilities in later age.

#### **4.2.4 Reducing Dependency: what alternative models of care are being considered currently for the future?**

- (a) Support and strengthen the BEM Elder Centre base, particularly day care. Elders can remain at home and yet activate social contact at the day centres. Initiate, fund and direct work aiming at healthy independent ageing, with positive mind and body in BEM elder Centres.
- (b) Housing circumstances need to be improved with greater aids to remain independent at home.
- (c) Home care support needs to be increased and supported by qualified and competent staff.
- (d) Development of specific complimentary programmes like Yoga, meditation classes, Tai chi, traditional herbal and massage techniques should be used and positively promoted, within BEM communities.
- (e) Transfer learning of specific methods which relate to successful ageing should be built and used as part of the community's memory bank for current and future generations. It can also be useful for reminiscence work particularly for people with dementia.
- (f) The new Parliamentary bodies in Wales, Scotland and Northern Ireland have an excellent opportunity to build in at the outset the arrangements which will support effective care and independent ageing for BEM elders and carers in collaboration with BEM elder bodies in each area.
- (g) New roles (e.g. volunteering, short-term employment) of elders should be encouraged to break social distance between the young and old, thereby creating a better view on the 'value' of older people in society.
- (h) Mainstream authorities and funding bodies need to be guided to enact the elders' consistent recommendation in all three seminars – that the future model of care should attempt to cater for all minority ethnic groups 'under one roof', but still catering to specific person-centred requirements.

This would enable the individual to receive culturally sensitive care and enable greater understanding between communities and foster good community and race relations. 'We have had good experience here at the seminar coming from different faiths and cultures, why can't we think of this broadly?'



### 4.3 Conclusion

Throughout the seminar in various guises, questions such as ‘what next?’, ‘we have said these things before’ etc, continued to emerge emphasising the need for implementation of recommendations in order to make a real difference to peoples’ lives.

The fact that elders, carers and managers responded to our invitation to the seminar with only two weeks’ notice shows their continuing willingness to affect policy in the hope that there will be *significant* changes.

The recommendations proposed here are indicative of the elders’, carers and managers’ efforts to be a part of mainstream society, and not an adjunct.

This is what a modern society aspiring to be ‘inclusive’ needs to harness and support with directed resource strategies.

To do otherwise is to accept segmentation in care where the minorities may be structured into long-term *marginal* care services, struggling and seeking their own solutions to experience of ageing *without* adequate support for a dignified and worthy old age.

As Sir Herman Ouseley, Chairman of the Commission for Racial Equality, is quoted as saying,

*‘The UK’s black and minority ethnic older people have faced the experience of old age with remarkable aplomb. They are dealing with personal challenges of ageing and struggles for racial justice on a daily basis. Many individuals from these communities have also led initiatives which give social, cultural and spiritual support to older members and their communities.’*

*‘. . . I agree with the statements made by Mr Paul Boateng, Under Secretary of State for Health<sup>5</sup>, that ultimately the quality and security of the provision made available for the long-term of the elderly is the hallmark of a civilised society, and one by which we will all be judged. Governments, organisations, professionals, families with young and old all need to participate to ensure that such a goal is achieved.’*

Foreword in Patel, N, & Mertens, H.(eds.) *Living and Ageing In Europe: Profiles and Projects*, NIZW: Netherlands & CCETSW: London

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## Footnotes

- 1 Some delegates at the seminars commented favourably on the support provided by the National Lottery Charities Board in assisting their service development. Others also commented on how charities have a 'view' of what is best for BEM elders and carers, reflecting our comment that BEM elders are merely inserted into a concept of care which may be neither supportive to their real needs nor effect models of independent ageing. As charities become aware of BEM elder presence, these comments are critical in questioning the nature of their supportive role since through funding strategies they too can determine the course of BEM elder care developments in the future. Whether they support real innovations towards fulfilling old age or mere containment of BEM elders for passive ageing is something PRIAE will be examining.
- 2 We have from this section used BEM as a shorthand to refer to Black and Minority Ethnic people.
- 3 This is the symbol adopted by the city of Granada, Andalucia, Spain to reflect the same principle. It suggests the ability of people to exercise rights to maintain diversity and yet live and work in unity.
- 4 We have from this section used BEM as a shorthand to refer to Black and Minority Ethnic people.
- 5 Paul Boateng MP is now a Home Office Minister.

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# Appendix 1: The Perspectives of Elders, Carers and Managers on Long-Term Care

## 1. METHODOLOGY

### Background

In June, PRIAE had produced an Issues paper with recommendations on long-term care. The Commission's view was that a seminar method with the Issues paper as a background document would be a useful means for establishing the content and direction for long-term care from the perspective of elders and their carers from minority ethnic groups. Since black and minority ethnic organisations are critical suppliers of care, managers of such organisations would also be involved. Following the Commission's decision of 28 July that three seminars in association with the CRE should take place with a report by the end of September, the planning and organisation of seminars began immediately.

### Subjects and Criteria

A selected number of minority ethnic elders' organisations covering Day care, Residential care/Sheltered Housing, Nursing Homes and Carers were contacted. Two principles guided the invitations: (a) the need to cover a large geographical base rather than just simply the city where any one of the seminars was held and (b) that between the three seminars there should be coverage of several minority ethnic groups. As there were a limited number of seminar places, individuals and organisations could still take part in the exercise: PRIAE's background paper was sent to those who requested such participation. The short planning cycle circumscribed additional methods of work: all organisations were personally contacted by telephone and places were allocated for elder(s) and carer(s) to attend. This was followed up in writing with further details. The three-fold mix of a manager, elder and a carer applied to most organisations in day care, housing and carers groups. Appendix 2 provides the list of elders, carers and managers for each seminar.

### Locations and Distributions

Three seminars took place in Leeds (2nd September), London (4th September) and Edinburgh (11th September). Thirteen organisations with elders and carers attended the Leeds seminar – they were based in Bradford, Kirklees, Sheffield, Lancashire and Liverpool. The London seminar had fourteen organisations spanning as far as Bristol and Wales. For Edinburgh, sixteen organisations came from various parts of Scotland. The organisations' attended and/or invited shared between them several ethnicities and faiths: they ranged from Asian, Afro-Caribbean, African, Chinese, Vietnamese, Greek, Latin American, Iraqi, Turkish, Polish, Ukrainian, Greek and Turkish Cypriot with Christian, Islamic, Sikh, Buddhist, Hindu, Confucianist and Humanist backgrounds. Several organisations in other cities covering a range of ethnicities were also invited but all could not attend on the day. Facilitators were age-related subject specialists although their organisations are not covered in the findings. Interpreters were provided as required by the participants.

For the coverage in Wales and Northern Ireland, discussions were held with several individuals. PRIAE's background paper was sent to them inviting any



specific perspectives from Wales and Northern Ireland on long-term care for minority ethnic elders.

The structure of the seminar programme was built around the following:

- that black and minority ethnic elders, carers and their organisations, UK-wide, would have an opportunity to inform and contribute to the recommendations;
- that the Royal Commission would receive a Final Report on issues and recommendations on the long-term care for black and minority ethnic elderly;
- that this report would enable the Royal Commission to include black and minority ethnic elderly and carers' perspectives on long-term care in their Report to the Government.

### **Analysis**

The workgroups were divided into managers, elders and carers. Each was asked to consider the same four questions given below. These questions were sent ahead of the seminar day to enable prior preparation. A brief introductory exercise established the characteristics of the group. Each group had two facilitators to enable direction and note taking. The four questions were:

#### **(a) The appropriateness of current models of care**

Users and carers' experiences, views on choice and quality of current service provision in day care, residential/sheltered and nursing homes.

#### **(b) Accessing services**

The experience of carers/elders/managers engaging and co-ordinating services with social services, health and housing.

#### **(c) Planning and paying for long-term care**

The experience and effect of means testing and the practice of capped local budgets.

#### **(d) Reducing dependency**

What alternative models of care are being considered currently for the future?



## 2. PRINCIPAL FINDINGS

The detailed findings are presented in Table 3 which is subdivided to give the views of Elders, Carers and Managers. They are categorised in relation to the four questions above conducted at the three seminars in Leeds, London and Edinburgh between 2-11 September 1998.

**Note:** The following abbreviations are used in these tables:

1. BEM: black and minority ethnic for people, elders, carers, centres
2. HA: Health Authority
3. SSD: Social Services Departments
4. VS: Voluntary Sector
5. RRA: Race Relations Act 1976



Table 3: Detailed Findings from the Three Seminars

<b>MANAGERS' VIEWS</b>		
<b>Edinburgh</b>	<b>Leeds</b>	<b>London</b>
<b>1. Overall View – the appropriateness of current models of care</b>		
Flexibility needs to be incorporated, e.g.: <ul style="list-style-type: none"> <li>■ employing specialist workers</li> <li>■ using article 52(d) of RRA 1976</li> <li>■ make changes to training of services</li> </ul>	Current models may not be appropriate for BEMs, but it is a case of lumping everyone together and accepting them.	Mainstream services did not attract BEMs because: <ul style="list-style-type: none"> <li>■ not confident of the services they receive</li> <li>■ feared rejection</li> <li>■ not BEM friendly</li> <li>■ system not for them</li> </ul>
Overall care provisions are appropriate.	If services are taken up by BEMs there needs to be: <ul style="list-style-type: none"> <li>■ a sense of community</li> <li>■ easy access to services</li> <li>■ no waiting time</li> <li>■ key workers should be the same ethnicity</li> <li>■ help with language barriers</li> <li>■ understanding and provision for religious/spiritual needs</li> <li>■ services need to be localised</li> </ul>	BEMs feel: <ul style="list-style-type: none"> <li>■ services are not culturally appropriate</li> <li>■ services not appropriate for dietary needs</li> <li>■ staffing did not reflect community at large</li> </ul>
Mainstream had to acknowledge that: <ul style="list-style-type: none"> <li>■ there were different communities and needs</li> <li>■ needs change over time and across generations</li> <li>■ current thinking and planning is based on stereotypical assumptions</li> </ul>	Mainstream providers play a 'numbers game' when catering for BEMs, e.g. the Vietnamese community are 'lumped' together with the Chinese community and therefore: <ul style="list-style-type: none"> <li>■ their needs are not met</li> <li>■ there is no Vietnamese key worker helping to bridge gaps</li> <li>■ and consequently the community look after their own</li> </ul>	The prevailing view of mainstream providers is that the needs of BEMs are extra.
Some mainstream service providers did not and would not consider the needs of BEMs.		Mainstream services not integrated to cater for diversity.
Numbers game' is used to deny appropriate provision (e.g. in rural areas).		Suggestion – to avoid isolation of a BEM person in one particular home multiple placements are worth considering.
Provision in private nursing homes is problematic because of issues relating to: <ul style="list-style-type: none"> <li>■ training</li> <li>■ language</li> <li>■ services on offer</li> </ul>		



Edinburgh	Leeds	London
<p>The SEMRU/VOCAL report should be commended for highlighting the need for more BEM staff</p> <p>Fook Hong/Sehat Project – provides a useful and transferable model for community training and delivery of services</p>		
<p>More data is required at a national level, especially in non-urban and rural areas about the number of elderly BEMs</p> <p>More evidence of actual needs is required on communities or voluntary projects with limited resources. Without such evidence providers will not discuss issues</p>		
<p>Planners etc should be informed through their own use of data collected on BEMs and national research and statistics on,</p> <ul style="list-style-type: none"> <li>■ issues (legal) relating to the duties of providers and the use of public money – if sections of the public are excluded from receiving appropriate services, then planners need to be made aware of their legal duties</li> <li>■ how to recognise needs, since if this is not known then there will be no attempt to encourage access, co-ordinate services or have a long-term strategy leading to better treatment of BEMs</li> </ul>		
<p>There needs to be real commitment with genuine intentions to seek appropriate and imaginative solutions to the problems of different communities, and not just ‘noble expressions’.</p> <ul style="list-style-type: none"> <li>■ Carers had to provide meals 3 times a day, which adds to their own stress as expressed in one case</li> <li>■ There was the view that social workers avoided cases involving BEMs since they were ‘more complicated’</li> </ul>		



Edinburgh	Leeds	London
<p>Interpreters were rarely used in doing care assessments suggesting that,</p> <ul style="list-style-type: none"> <li>■ better training is required</li> <li>■ BEM organisations should be involved more</li> </ul>		
<p>If care is to be provided in the community, carers need support – e.g. respite services.</p>		
<p><b>2. Accessing Services – the issue of choice and co-ordination of services between social services, health services and housing</b></p>		
<p>BEMs are denied a choice in many cases.</p>	<p>Choice for BEMs was limited:</p> <ul style="list-style-type: none"> <li>■ some services had BEMs, but all BEMs were squeezed into this</li> <li>■ BEMs who wanted appropriate services were limited in what they received</li> </ul>	<p>For BEMs, not only was choice limited but</p> <p>The quality of services varied where provisions did exist, e.g. residential care was under-resourced.</p>
<p>Communities had little opportunity to make an informed choice – e.g. Edinburgh Sheltered housing.</p>	<p>Cultural and language barriers affected housing choice. Other issues related to:</p> <ul style="list-style-type: none"> <li>■ changes in extended family due to changing culture</li> <li>■ BEMs having different social and economic stresses</li> <li>■ among Muslim elders there was the stigma attached to parents leaving family home for sheltered housing</li> </ul>	<p>The cost of residential care provision was the overriding factor for SSDs, rather than the quality or appropriateness of the care provided.</p>
<p>Sheltered housing for Chinese Community in Edinburgh and Dundee:</p> <ul style="list-style-type: none"> <li>■ evidence gathered to support this provision</li> <li>■ convinced housing association and LA of the need for this provision</li> <li>■ they approached Scottish Homes for funds</li> </ul>	<p>Housing solutions included building extensions to existing family homes.</p>	<p>Services should be specific to needs, for example:</p> <ul style="list-style-type: none"> <li>■ day care centres opening doors to people with dementia proved detrimental to staff and users</li> <li>■ dementia cases automatically sent to BEM day care project</li> </ul>
	<p>Funding to the voluntary sector decreasing</p> <p>No specific allocation within health or SSO for meeting BEM's needs</p> <p>No BEM staff at high levels to influence budget allocations</p> <p>Attention should drawn to anti-discriminatory practices and policies, beginning with an audit of existing practices and policies</p>	



Edinburgh	Leeds	London
<p>Carers resentful of consultation that does not produce results. Suggested that:</p> <ul style="list-style-type: none"> <li>■ one-stop approach would have benefits</li> <li>■ advocacy processes should be made more widely available to BEMs</li> </ul>	<p>Accessing services is very difficult:</p> <ul style="list-style-type: none"> <li>■ for example for one Sheffield voluntary group assessments by HA/SSD took one month or more. There were exceptions – e.g. in Kirklees there was a good relationship with the SSD unit.</li> <li>■ suggested that joint assessment was preferable, but SSD do not want erosion of power</li> <li>■ user apprehension about appropriateness of service</li> <li>■ Primary Care Groups are a way of improving access and co-ordination</li> </ul>	<p>Consultation ‘phoney’ – they are lengthy and detailed but voluntary sector organisations are ultimately still given what authorities <b>think</b> is needed. Good examples and suggestions included:</p> <ul style="list-style-type: none"> <li>■ Ealing – an exception since here outreach approach to consultation allowed those most in need to have a voice and be heard</li> <li>■ to improve access and co-ordination a one-stop shop is likely to be beneficial (e.g. Hillingdon)</li> <li>■ multidisciplinary teams should be set up to carry out assessments</li> </ul>
	<p>Users do not know about services because of a lack of marketing and promotion. If information is available it is only in English. However, in Bradford the local authority does target BEMs using road shows to highlight services and an Age Link line with information in several languages</p>	<p>Marketing of services by HA/SSD – information should be accessible, consistent, and user-friendly.</p>
<p>Example of problems with discharge:</p> <ul style="list-style-type: none"> <li>■ Elder sent home from a nursing home. Family simply told ‘social work’ did not have resources.</li> </ul>	<p>Hospital discharge is a problem:</p> <ul style="list-style-type: none"> <li>■ Absence of good pre-discharge planning – however, a good example organised by Bradford SSD where volunteers visit patient in hospital to talk to them before discharge.</li> <li>■ Hospital staff cannot interpret community-based services.</li> </ul>	<p>There is zero co-ordination in hospital discharge.</p> <ul style="list-style-type: none"> <li>■ Primary Care Staff said to be best placed to provide advice and information to people being discharged from hospitals.</li> </ul>
<p>Confusion over roles of health service and SSD.</p> <p>Example of positive collaboration between agencies: one project worked with social work department to produce accessible and appropriate services.</p>	<p>HAs and SSDs fall out over who should pay for what:</p> <p>HAs, SSDs and VS seldom get together for planning, except in joint finance initiatives (JFI)</p> <p>JFI is good because it brings the two groups together, but bad because this marginalises services for BEMs.</p>	<p>VS to provide total care for individual - need only one point of contact at HA/SSD end. However, there is a big divide between HA and SSD.</p> <p>HAs and SSDs had a role in briefing VS.</p> <p>JFI good, but monitoring and evaluation is too time consuming (e.g. Ekta Project – 2 posts funded by JF will be funded by SSD mainstream).</p>



Edinburgh	Leeds	London
<p>Appropriate provision for EM communities competing with everyone else.</p> <p>Should use a different standard of measuring cost-effectiveness of service – not unit cost. BEM's costs need not be extravagant – they have a right to have their needs met.</p>	<p>Training important to:</p> <ul style="list-style-type: none"> <li>■ improve access</li> <li>■ knowledge of services in mainstream and VS</li> <li>■ improve psychiatric assessments (problems with cultural misinterpretation)</li> </ul>	<p>Funds for meeting BEM needs should be 'ring fenced'.</p>
<p>Complaints,</p> <ul style="list-style-type: none"> <li>■ people must be made aware of their rights</li> <li>■ how to complain</li> </ul> <p>Independent and expert views on BEM's needs were appropriate in complaints.</p>		
<p><b>3. Planning and paying for long-term care</b></p>		
<p>Question of payment – rooted in the present.</p>	<p>Confusion and resentment:</p> <ul style="list-style-type: none"> <li>■ NHS – free</li> <li>■ LA Care – charged; care refused even though need existed.</li> </ul>	<p>BEMs reluctant to pay for care therefore,</p> <ul style="list-style-type: none"> <li>■ kept at home longer, despite high care needs</li> <li>■ reduced frequency of using services</li> <li>■ elder abuse</li> </ul>
<p>Health Green Paper and:</p> <ul style="list-style-type: none"> <li>■ the link between life circumstances and health inequalities</li> <li>■ action to tackle social causes of poor health</li> </ul>	<p>Explanations for not wanting to pay included:</p> <ul style="list-style-type: none"> <li>■ 'contributed to that cost through taxes'</li> <li>■ extended families could not afford this</li> <li>■ robbed people of funds to go back home</li> <li>■ elders did not want to be a financial burden to their family</li> </ul>	<p>No views on whether services should be free or paid for.</p>
<p>Home ownership in Scotland:</p> <ul style="list-style-type: none"> <li>■ not a sign of affluence even though more BEMs own homes than whites</li> <li>■ must look at institutional discrimination, location, condition of housing, over-crowding</li> </ul>	<p>People did not like to disclose financial information.</p>	
<ul style="list-style-type: none"> <li>■ Employment for BEMs – low paid jobs catering, hotels.</li> <li>■ Scottish office – BEMs unemployment 3:1 compared to white unemployment</li> <li>■ Higher self-employment among BEMs</li> </ul>	<p>In financial assessments, income of entire household taken into account. Led to:</p> <ul style="list-style-type: none"> <li>■ resentment by some family members</li> <li>■ family break up</li> <li>■ elder abuse</li> </ul>	



Edinburgh	Leeds	London
<b>4. Reducing Dependency – what models of care are currently being considered for the future?</b>		
<p>Flexible approach required:</p> <ul style="list-style-type: none"> <li>■ e.g. in Dundee there is a non-traditional lunch club which provides opportunities for social and recreational activities.</li> </ul>	<p>Expanded occupational therapy units.</p> <p>More home based support.</p> <p>More resources to deliver promises.</p> <p>Qualified trained staff – empathetic and competent.</p>	<p>More health visitors for older people.</p> <p>Emphasis on complimentary therapies targeting physical, mental and spiritual needs.</p> <p>More one-stop shops.</p>
<p>Sheltered housing which involves and encourages ownership.</p>	<p>System of ‘Halfway Homes’ – for recuperation and rehabilitation, after hospital discharge. But who pays?</p> <p>Total shelter – all services on site and user empowerment.</p>	<p>‘Very sheltered’ housing.</p> <p>Day centres funded to do dependency-reducing work (Funding from Independent Living Foundation).</p>
<p>Debates are important that:</p> <ul style="list-style-type: none"> <li>■ are not affected by views such as ‘they look after their own’</li> <li>■ require having to hand BEMs data, needs assessments and demographics</li> </ul> <p>Debates will help in planning to decrease dependency – every provider should be able to say who is using a service, who is not and who ought to use the service.</p> <p>A group should be set up that helps in planning, assessing and reviewing; it should be comprised of VS, CRE etc. and be accountable to the Scottish Parliament.</p>	<p>Good literature to help make family and older people aware that dependency arises when everything is done for the elder – maintain independence.</p> <p>Be on interview panel – about who helps them.</p> <p>Recognition that services will have to be paid for.</p>	<p>Adopt proactive approach to health and education.</p>



CARERS' VIEWS		
Edinburgh	Leeds	London
<b>1. Overall View – the appropriateness of current models of care</b>		
<p><b>Background</b></p> <p>Service providers do not acknowledge BEM's carers or respond to their needs. There is a general lack of understanding of the reasons for why BEMs are not accessing mainstream services:</p> <ul style="list-style-type: none"> <li>■ Lack of cultural awareness</li> <li>■ Non-representative workforce</li> <li>■ Negative attitude of service providers</li> </ul> <p>The above then results in models of care that lead to,</p> <ul style="list-style-type: none"> <li>■ more demands on the individual, their families and communities (i.e. internal solutions)</li> <li>■ the attitude of 'they look after their own' prevailing.</li> </ul> <p>There is no strong feeling about who should provide the services, but that such services should be easily and equally accessible.</p> <p><b>Mainstream providers</b></p> <p>Care by the mainstream does include meals on wheels for Chinese and Asian clients, but this is a limited service and results in frustration. There is increasing isolation of BEMs in various mainstream provisions – day, respite, residential and nursing home care. This was partly because there was an absence of staff from the same ethnic background, resulting in a lack of communication and stimulation of BEM elders.</p> <p><b>BEM providers</b></p> <p>Although care provided by black voluntary organisations resulted in a high degree of satisfaction there were real concerns regarding the precarious financial position of such organisations.</p>	<p><b>Background</b></p> <p>People in government who can make a change need to look at black people in care. The following are illustrative examples:</p> <p><b>Mainstream providers</b></p> <p>Support for carers is non-existent. They rely on family support. It is clear that family carers see it as their duty and/or obligation to support an elder and such carers should be supported.</p> <p><b>BEM providers</b></p> <ul style="list-style-type: none"> <li>■ Sadeh Lok is for the Asian elderly and encourages people to attend for home care and in attaining food provisions.</li> <li>■ Person A is disabled with arthritis of the spine. She lost her husband 4 years ago, has 3 children, retired at 43, looks after her mum of 71 years who is almost crippled and is catered for by Milton House.</li> <li>■ Ms B is from the poor Ukrainian population, which is coming more to the attention of social services in Bradford. Her mum has rheumatoid arthritis. She got involved with social services on a part-time basis as an informal social worker. Her knowledge of Latvian, Polish etc can be beneficial to those from the local community trying to access services.</li> <li>■ Mrs C who is with the Black Elders Association (1955) was 75 last week and lives in a big house. She has difficulty going up the stairs to use the toilet, and social services cannot provide a downstairs toilet. She does, however, receive care at weekends and meals on wheels.</li> </ul>	<p><b>Background</b></p> <p>There is a lack of services for BEM carers and a lack of awareness amongst the mainstream of their needs. Although one project may meet their needs, the range of services are inadequate.</p> <p><b>Mainstream providers</b></p> <p>The SSD do not appear to be aware of BEM's needs. For example,</p> <ul style="list-style-type: none"> <li>■ there are no Chinese support staff and consequently there is no Chinese food available as a meals on wheels service – subsequently there are no services for Chinese in some boroughs.</li> <li>■ There are not enough nursing/residential homes available, respite services, dial-a-ride services or Chinese speakers.</li> <li>■ Carers have no breaks and are not aware of services available to them.</li> <li>■ There is no specialist care for dementia – it is called 'old age'.</li> </ul> <p><b>BEM providers</b></p> <ul style="list-style-type: none"> <li>■ Mr D runs a day centre for those with dementia, which provides a door-to-door bus service, activities for those in a wheel chair, a Punjabi speaking support network and offers 'breathers' for carers. Although the clients are mainly Asian the inclusion of Italians, French and West Indians means that sign language is used due to a lack of a common language.</li> <li>■ ASRA provides care for elderly Asians. However, when advanced dementia develop they are usually transferred to a nursing home for which there can be a 2-year wait. It is subsequently common for patients to die 2/3 months after the transfer, which is normally to an English-speaking home which does not cater for the BEM elders' cultural and spiritual needs.</li> <li>■ Mr E cares for his 90-year-old mum; his own wife is ill.</li> <li>■ Ms F is a national interpreter who helps mainstream services in bridging gaps with BEMs.</li> </ul>



Edinburgh	Leeds	London
		<ul style="list-style-type: none"> <li>■ Ms G who herself cares for her daughter with cerebral palsy, also personally supports and provides relief care for elderly people. However, demand outstrips supply and the co-ordinator has to turn people down.</li> <li>■ Person H is a housebound service which provides support with provisions for shopping, advocacy, language, hospital and cooking.</li> <li>■ Ms I of ASRA provides an in-house service for residents (doctors, dentists, religious and cultural needs, prayers once a week, hygiene service for carers etc).</li> <li>■ Ms J cares for her mum who recently had a stroke leaving her with paralysis of the left side of the body. Her mum is totally dependent on full-time care. However, their current living accommodation is unsuitable for the new medical needs – therefore liaison with professionals from various organisations has been essential in an attempt to re-house to a suitable property. Her elder sister is also a main carer – however she has Lupus an immune disorder. There is essentially a shift system of care amongst family members.</li> </ul>
<p><b>2. Accessing Services – the issue of choice and co-ordination of services between social services, health and housing</b></p>		
<p><b>Barriers to access</b></p> <p>Lack of knowledge about what's available and how the system operates</p> <p>Although there is too much dependence on translated materials as a means of providing information no work has been done on appropriate methods of dissemination</p> <p>Carers are more likely to approach their GP rather than social services. If this is the case then the GP's role in information provision is crucial.</p>	<p><b>Barriers to access</b></p> <p>Financial stresses. For example, Mrs C's brother is crippled and sister-in-law has cancer. She has saved money for them and cared for them till they died. Although she herself is a carer she is not accessing services because there are not many residential homes and consequently she is isolated.</p> <p>Language barrier – for example, a Ghanaian elder who was silent at a day centre was considered dumb. However, when a Ghanaian student visited the centre they spoke in Kentaku.</p>	<p><b>Barriers to access</b></p> <p>Stereotypical views by social services – 'daughters will help' – i.e. myths about the family.</p> <p>There is no consideration of family resources.</p> <p>Providers need to update their knowledge of family structure.</p> <p>Prejudice and racism.</p>



Edinburgh	Leeds	London
<p><b>Issues</b></p> <p>There should be Training for specialist interpreters working in social care and health.</p> <p>One carer, who received help, did not understand who provided this help until a black project group got involved.</p> <p>Transport.</p> <p>People became came to the attention of health and social services at crisis points.</p>	<p><b>Issues</b></p> <p>There is a fear of old age.</p> <p>Pride – elders do not want to get something for nothing.</p> <p>Reluctance to receive help on part of elder – suspicious of reasons for help.</p> <p>One 90-year-old refused to accept help with cleaning – he felt he was fit and capable of caring for himself.</p>	<p><b>Issues</b></p> <p>Social Services say client is not in bad shape. For example, a 74-year-old Chinese carer minding a 92-year-old sister and husband is, in the view of social services – not a priority since the sister can walk. However, she needs help with cleaning and carrying.</p> <p>One Chinese doctor in Westminster was frustrated by the demand.</p> <p>There were also inter-ethnic issues. For example, a Punjabi speaking support worker could not understand a Punjabi speaking person from ‘back home’.</p> <p>Leaflets are a waste of time and money because clients lack reading skills.</p> <p><b>Quotes</b></p> <p><i>‘Our children are our NI because back home we haven’t got health services.’</i></p> <p><i>‘For paying taxes I’m treated as English; for getting services I’m treated as Asian.’</i></p> <p><i>‘NI goes to the Inland Revenue. We need support. My daughter should not be expected to care for me.’</i></p> <p><i>‘I do not pay NI for the Gurudwara!’</i></p>
<p><b>3. Planning and paying for long-term care</b></p>		
<p>There was a very strong feeling amongst BEMs that they had already paid or were paying for care through taxation and NI.</p>	<p>Care should be free.</p>	<p>We help the state via NI contributions.</p>
<p>Two-tier care system may arise – because issues related to unemployment and entitlement had not been considered adequately.</p> <p>Lack of uniform changes for services across Scotland. Carers preferred standard charges.</p> <p>One carer withdrew from home help service because of charges introduced. Financial assessment was made, but benefits not maximised – she could not afford the home help service.</p>	<p>The needs of carers are recognised and money should be set aside for this.</p> <p>Question raised – where are all the taxes going?</p>	<p>The role of informal care needs to be recognised.</p>



Edinburgh	Leeds	London
<p><b>4. Reducing Dependency – what models of care are currently being considered for the future?</b></p>		
<p><b>General</b></p> <p>The views of all carers was that,</p> <ul style="list-style-type: none"> <li>■ elders be treated with dignity and respect</li> <li>■ services work towards maximising independence.</li> </ul>		<p><b>General</b></p> <p>Current provisions are patchy. Consequently there should be a national exercise to find out what the current provisions are, who provides them and to identify the gaps in provision.</p>
<p><b>Examples</b></p> <p>Day centres should be flexible and imaginative so as to:</p> <ul style="list-style-type: none"> <li>■ enable carers to have a ‘normal’ life</li> <li>■ provide intensive domiciliary support when required.</li> </ul> <p>Residential care – not an option since BEM elders were negative to this.</p> <p>Sheltered housing for BEM elders should be considered – e.g. Cathay Court creates and fosters a sense of community. Sheltered housing is a response to changing family and community structures which are leading to them being unable to care for the elderly.</p> <p>Specialist units – e.g. for dementia patients within sheltered housing should be considered.</p>		<p><b>Examples</b></p> <p>Family Link or alternative – social services could police/monitor this.</p> <p>Recognise role of informal carers – pay them.</p> <p>Involve older people in community:</p> <ul style="list-style-type: none"> <li>■ create employment e.g. 2 hours at Tesco, volunteer work etc. should be valued.</li> <li>■ Increase the idea of culture based communities (use churches – pay rent).</li> </ul> <p>Alternative Models are difficult to consider – not even basic needs are being met at present.</p>
		<p><b>Issues</b></p> <p>Home based day care – an invasion of privacy.</p> <p>BEM communities dislike volunteering.</p> <p>Rethink attitude towards work and life – work is essential for living.</p> <p>Chinese find it difficult to think about alternatives to care when there is no care.</p> <p>There needs to be a greater understanding and appreciation for the fact that communities are heterogeneous.</p>



<b>ELDERS' VIEWS and RECOMMENDATIONS</b>		
<b>Edinburgh</b>	<b>Leeds</b>	<b>London</b>
<p><b>Characteristics</b></p> <p>There were 8 men in this group (age: 65-91 years) of Indian/Pakistani descent who came to the UK (Scotland) via Kenya; West Africa; Hong Kong; South Africa and France.</p>	<p><b>Characteristics</b></p> <p>There were 6 men and 2 women in this group (age: 60-78 years with one future elder who was 25 years old) who came from Nigeria (to Sheffield), Pakistan and Uganda; (Bradford, Lancashire and Leeds); Jamaica (Leeds); and India (Bradford).</p>	<p><b>Characteristics</b></p> <p>There were 4 men and 4 women in this group (age: 54-86 years, with one future elder who was 29 years old) who came from Sri Lanka, India, Jamaica, Madagascar (of Indian origin), Hong Kong, Columbia and London – all now live in London.</p>
<p><b>1. Overall View – the appropriateness of current models of care</b></p>		
<p><b>Satisfaction rates</b></p> <p>The group stressed the importance of faith as one gets older, but accepted that there was a need for balance between religion and hospital care.</p> <p>There was agreement that religion, food and language were all-important aspects of appropriate care. It was felt that a lack of resources from government to meet demands made it difficult to incorporate these into care for elderly BEMs.</p> <p>In Scotland (Fife) a lack of adequate care was also reflected by the lack of opportunities in which to meet others from the same ethnic background – i.e. Chinese or Asian elders? The vast distances in Scotland, which made it more difficult to meet people of the same ethnicity, exacerbated such problems.</p> <p>It was agreed that in contrast to the mainstream, BEM centres brought enjoyment and appropriate activity. However, it is also clear that good ideas need support – particularly when considering rural BEM centres.</p> <p>Others stressed the point that elderly BEMs were last in the queue when it came to receiving services, and many could find nothing like a BEM centre in their local areas.</p>	<p><b>Satisfaction rates</b></p> <p>The group was content with the level of personal care received, whether at home or in a residential unit because it was culturally appropriate. For example, one elder's spouse died of cancer but felt that she had received good care.</p> <p>However, the group felt that BEM centres were good and removed isolation. Moreover, it was commented on that racism was institutionalised: some elders expected to be short-changed or treated unequally in the mainstream.</p> <p>The lack of knowledge and information about what services are available (home help, housing etc.) and how to obtain them if required was an issue. Also, whilst often elderly BEMs understood what was needed (e.g. modifications to the house) there was no support in aiding elders to continue to live in their own house.</p> <p>In response to housing problems it was expressed that BEMs had themselves taken the initiative to control, plan, design and manage the housing schemes that were appropriate for families with elders, but that whilst this was expanding the current waiting list was long.</p>	<p><b>Satisfaction rates</b></p> <p>There was a preference for culturally familiar and appropriate care centres.</p> <p>A women only house which had good facilities and which was well managed was a model to aspire to.</p> <p>Although day centres for elderly BEMs are used by elders to meet, keep busy, eat and enjoy, it is clear that funding is finite. If these centres were closed then this would end visiting to other centres where elderly BEMs do not feel comfortable.</p> <p>One BEM centre does a lot in trying to cater for every aspect of life of the elders, but there are only two part-time workers serving a whole community.</p> <p>Home care was inadequate – elders said they received only one hour a week.</p> <p>There is also a lack of information and knowledge of services available – this is made worse due to language barriers.</p>



Edinburgh	Leeds	London
<p><b>Forecasting changes</b></p> <p>Family structure changes are likely to push housing issues amongst elderly BEMs further up the agenda – it is clear that at present the demand is not huge, but this is likely to change.</p>	<p><b>Forecasting changes</b></p> <p>The first generation of elders do not receive the help they need and have settled for less and inappropriate services. They have tolerated poorly funded organisations.</p> <p>The second generation will challenge this status quo in meagre care provisions. Therefore, authorities need to be better prepared.</p>	
<p><b>Recommendations</b></p> <p>Need BEM centres.</p> <p>Need financial support and staffing to expand and cater for rural BEM centres.</p> <p>Health services needed to respond appropriately to certain aspects of care – e.g. food and communication.</p> <p>The ‘they look after their own’ attitude needed to be excised from mainstream thinking.</p> <p>Elders programmes on TV in day centres.</p> <p>Model of future care: BEM groups of different faiths, languages etc under one roof in small numbers.</p>	<p><b>Recommendations</b></p> <p>The choice and range of service needed to be improved. Already some good examples of housing and day care centres exist since ‘we are using them presently’ – but these need to be more widely applied.</p> <p>It was recommended that research should be done on housing needs of those close to retirement age.</p> <p>People needed to be made better aware of services available – information and dissemination issues.</p> <p>People from BEMs should be more involved in service delivery.</p> <p>There should be multi-faith visiting groups for elders in hospitals to help reduce the isolation. Presently, families are unable to visit or are limited or restricted in their visits.</p>	<p><b>Recommendations</b></p> <p>Need to increase the choice, range and funding base of BEM centres.</p> <p>BEM elders come from all over and are concentrated in one centre. Since the numbers of BEM elders are few and they come from various locations, the relevant authorities in these different localities should all contribute to a single expanded centre with a wider range of services.</p> <p>Appropriate mainstream funding should be re-directed to BEM centres since they are already catering for elderly BEMs – in essence a saving for the system.</p>



Edinburgh	Leeds	London
<p><b>2. Accessing Services – the issue of choice and co-ordination of services between social services, health and housing</b></p>		
<p>There is a general lack of information, communication and interpreters in aiding to access services.</p> <p>Although there is easy access to GPs there is a difficulty in communicating needs.</p> <p>A lack of knowledge about the range of services.</p> <p>Housing is allocated in unsafe areas and there is unequal treatment in this service.</p> <p>Although BEM centres are relied upon to provide care they are poorly resourced.</p> <p>Feeling of being discriminated against because of language or colour – more so in England than in Scotland.</p> <p>Interpreters need information and support to go beyond simply translating.</p> <p>Problems with the Immigration service. For example, an 85-year-old brother was not allowed to celebrate his young brother’s golden anniversary from India</p>	<p>Mainstream professionals give negative responses – e.g. either does not give services (e.g. OT) or they do not respond adequately.</p> <p>Experience inequality – although Whites are able to access the full range of services, BEM elders do not know what is available and, if they do, often need a third party to make things happen.</p> <p>The level and amount of care depends on how able you are – e.g. how ill you are according to input from doctors or health visitors. However, what if such an assessment is not made at all or is inadequate?</p> <p>Council tenants get better provision than those do in private accommodation.</p>	<p>Primary care problems – GPs do not explain things and the 75+ check are not often done.</p> <p>Interpreters alone are not enough since GPs do not give adequate explanations.</p> <p>There are too many agencies to deal with for one problem.</p> <p>There are cases where elderly BEMs have been in the hospital for weeks with inadequate or little food – no one explained why this was so. Moreover, if you cannot speak English then there is no choice.</p>
<p><b>Recommendations</b></p> <p>An end to ‘hush-hush’ system – improve information and communication on services and benefits.</p> <p>Stop just doing translation of leaflets – need a real concerted communication programme</p> <p>Need a campaign to increase knowledge on benefits and take up.</p> <p>Increase racial harmony and stop racial discrimination.</p> <p>Those who are disabled and elderly should be supported more – i.e. more home care.</p> <p>‘Equalise’ cost of travel using different modes of transport – i.e. rail and bus. This would make travel costs less of an issue.</p>	<p><b>Recommendations</b></p> <p>There should be a better information and communication system that does not only rely on translators.</p>	<p><b>Recommendations</b></p> <p>Improve access to Interpreters for BEMs</p> <p>Interpreters need training, so as to be able to do more advocacy work and run advocacy schemes within BEM centres.</p> <p>Minority groups need to learn from each other (black and white).</p> <p>Need to learn from ‘success’ stories of BEMs and thereby improve services.</p>



Edinburgh	Leeds	London
<p><b>3. Planning and paying for long-term care</b></p>		
<p>Home care services are useful and therefore should be free.</p> <p>Insufficient pension to meet all demands – i.e. care expenses.</p> <p>Knowledge of benefits and entitlements poor.</p> <p>Felt that they have already paid – yesterday – for today’s care. Have worked very hard in younger life to secure comfortable future. The state has a responsibility to provide housing, health and social care.</p>	<p>Lack of information</p> <p>Capped budgets a great problem.</p> <p>Busy workloads, shift work etc makes it difficult to contact agencies relevant to BEMs.</p> <p>Voluntary groups – temple, church and other group centres provide crucial provision. But these centres are subsidised. If costs increase elders cannot meet this. Therefore there is low demand and a false idea that such centres are not needed.</p> <p>BEM attitude: ‘work hard to leave something for your children’. However, when BEMs think of paying for care they forget, as one elder put it: ‘thinking of back home, you pay or die’.</p>	<p>Cultural attitude:</p> <p>Will not enjoy eating if don’t pay . . . but have paid at one time.</p> <p>Not enough money to live on so how can I pay for care?</p> <p>As a woman I have not worked, but now in old age I need to be economically independent.</p> <p>High unemployment so savings not built up, so difficult to pay for care.</p> <p>Means test justified if large funds accumulated.</p> <p>Meeting appropriate care essential – BEM centres are doing this so should be funded.</p> <p>Capped budgets a great problem – chasing other sources to fund appropriate care.</p>
<p><b>Recommendations</b></p> <p>Charges will create disincentive to save in working life.</p> <p>Charges will increase dependency and not independent living – e.g. making the cost of rail transport equivalent to free bus travel encourages activity and reduces social isolation, leading to more independence.</p>	<p><b>Recommendations</b></p> <p>Benefits, Pensions and Housing – majority community has full pensions, whereas BEM elders need top up means-tested benefits, and yet ‘we worked long and hard’.</p> <p>Some elders still have commitments to family back home. Social Services Assessment must consider this.</p> <p>Problems of income assessment – incorrectly done.</p>	<p><b>Recommendations</b></p> <p>Materials cost more for an appropriate service to be provided – capped budget resource must therefore change for appropriate care to continue.</p> <p>Low pension income should be recognised.</p> <p>Need to fight racial discrimination in care and assessments.</p> <p>Group agreed on the principle:</p> <ul style="list-style-type: none"> <li>■ ‘those who have the means must pay those who have no means must receive care. This must occur without neither hesitation nor humiliation’.</li> </ul>



Edinburgh	Leeds	London
<b>4. Reducing Dependency – what models of care are currently being considered for the future?</b>		
<p>Culturally wish to remain independent in old age.</p> <p>Need alternative health supporting methods – e.g. traditional methods, massage etc as well as medication.</p> <p>Controlling diet and having a better attitude to growing old.</p>	<p>Healthy lifestyles – for example, promote vegetarianism and the use of herbal and traditional medicines.</p> <p>NHS should support use of Homeopathy and massage.</p> <p>Remain active and independent.</p>	<p>Less dependency on the state since already not receiving all services.</p> <p>Community profile may change as family structure changes in future with different patterns of care needing to be considered to account for this.</p> <p>Need to be economically independent – however, pensions are low amongst BEMs.</p> <p>Need to start planning for old age and be less dependent on state – however, this is difficult due to discrimination in jobs and pay.</p>
<p><b>Recommendations</b></p> <p>Interesting and active programmes need to be developed to stimulate intellectual and social enjoyment of activities.</p>	<p><b>Recommendations</b></p> <p>Monitor needs of elders since they change over time.</p> <p>Care system to have built-in flexibility.</p> <p>Should be a greater mix between different ethnic groups in services. Some experimentation is needed like Milton House where there is a mix of ethnic groups.</p> <p>Change attitude of the system to give elders what THEY need and NOT what providers think they need. Elders should be more involved in service design, planning and its delivery. There should be more inter-mixing between the young and old.</p> <p>Flexibility in care should be emphasised. For example, some people do not like residential care but still end up with this.</p>	<p><b>Recommendations</b></p> <p>Support healthy ageing, positive mind and body – increased yoga, meditation classes etc in BEM centres.</p> <p>Greater emphasis on young and old mixing.</p> <p>Encourage greater generosity to BEM centres among the very rich in the community.</p> <p>Better care at home – i.e. more and appropriate home care support.</p> <p>An increase in caring hours.</p> <p>A flexible care system is needed so as to respond to changing living arrangements in the future.</p>



## Appendix 2: Speakers and Delegates Lists

### PRIAE

Policy Research Institute on Ageing and Ethnicity  
University of Bradford Management Centre

### CRE

Commission for Racial  
Equality

### PRIAE – CRE SEMINARS

**Black and Minority Ethnic Elderly and Carers' Perspectives  
on Long Term Care  
A seminar on behalf of the Royal Commission  
on Long Term Care for the Elderly**

#### Leeds Seminar at Civic Hall, 2nd September 1998

Organisation	Managers' Group	Elders' Group	Carers' Group
Araam Day Care Centre Aashiana Housing Association	Navinder Uppal	Mr A Piracha Mrs Piracha	
Beckfield Residential Unit	C. Sampson Theresa Vaisalaevich		
Bradford Community Health Council Gulberg Community Resource Centre	Sharanjit Boughan Arif Iqbal	Mr K Mittal Mr E White	Mrs Reid
Leeds Black Elders Association Mary Seacole Nurses Association Milton House	Emutel Grierson-Sesay Jean Perkins Jenni Bradley	Jawan Agha	Jashoda Billo
Sadacca Elderly Day Care Centre Sadeh Lok Housing Association Leeds Vietnamese Community	Adebola Fatogun Tejinder Birk Hoang Doan	Ms Lawrence	Ms P Bennette Ms Narinder Sain
Ukranians Together in Age Dept. of Health (London) Dept. of Health (Leeds) University of Leicester Edge Hill College, Liverpool Leeds Social Services Department	Irene Diakin Raymond Warburton	Ulric Murray	Savita Katbamna Shirley Mashiane-Talbot Merrill Liburd

#### Speakers, Staff and Interpreters

Cllr. Hutchinson, Chair of Race Equality Committee, Leeds  
Cllr. Jones, Chair of Social Services Committee, Leeds  
Mr. Howard Leigh, Deputy Secretary, Royal Commission on Long Term Care for the Elderly  
Naina Patel, Sunjeeda Hanif, Beulah Mills  
Nirmala Bandopadhyay, Jagdip Passan

#### Also invited

Afro Caribbean Care Group, Manchester; Apna Day Centre, Leeds; Bangladesh Porishad Centre, Bradford; Hindu Cultural Centre, Bradford; Leeds Chinese Elderly Luncheon Club; Pine Court Housing Association, Liverpool; Somali Community Centre, Liverpool; United Caribbean Association, Leeds; Yemeni Carers Support Group, Sheffield; Asra Midlands Housing Association; and South Leeds Muslim Group.



London Seminar at the CRE Office, Elliott House, 4th September 1998

Organisation	Managers' Group	Elders' Group	Carers' Group
Age Concern England	Meena Patel		
Alzheimers Concern, Ealing	Kulbir Gill		Mr Gurdial Sandhu
ASRA Housing Association	Rishi Ramkissoon	Mr Nadrajha	Mrs Mistry
Bristol Community Growth & Support Assoc.	Emanuelle Adebisi		
Centre for Policy on Ageing	Tarek Qureshi		
EKTA Project	Ramesh Verma	Mr Panesar	Mr K Phull
Eastwards Trust	Kalyani Gandhi		Mrs Trivedi
Gita Foundation		Gita Prakash Balmukund	
Latin American Elderly Project		Lucy Janowicz	
London Chinese Health Resource Ctr.	Amy Wong		Mrs Chan
Multicultural Care Crossroads, Wales			Ms Sana Batros
Pepper Pot Club	David Idiabana	Gloria William	
WISE Education Project	Augustine Filson	A Porteous	
Great Wall Housing Ling Association	Mrs Lim	Mr Lai	Ms Kar

**Speakers, Staff and Interpreters**

Ms Gillian Farnfield, Royal Commission on Long Term Care for the Elderly  
 Naina Patel, Sunjeeda Hanif, Saqib Hanif, Nirmalya Bandopadhyay, Winnie Chin

**Also invited**

Bells Project, Hackney; Shakti Nursing Home; Mary McCormack; Camden Irish Pensioners' Network; Age Concern, Haringey; Cypriot Elderly and Disabled Group; and the Black Carers Project, Bristol.



**Scotland Seminar at Edinburgh City Chambers, 11th September 1998  
in association with VOCAL**

<b>Organisation</b>	<b>Managers' Group</b>	<b>Elders' Group</b>	<b>Carers' Group</b>
Aberdeen Chinese Elders Assoc.	Gregory Poon		
Age Concern Scotland			Helena Scott
Bharatiya Ashram	Mr Jyoti Hazra		Mrs Helen Hazra
Chinese Elderly Initiative	Mrs Li Fang Lamb Mr Noor Mohammed	Mr Wong	Mrs Lou
Dixon Carers Centre	Julie Young	Jasbir Kaur	
Dostana Association	Iftikhar Chaudhary	Mr Barkat Ali	Mr Sultan M Anwer
Edinburgh Chinese Elderly Support Assoc.	Ben Yuen	Mr I S Tang	
Glasgow Multicultural Health		Sheem Gill	
Mel Milap Centre		Mr S S Kohli Mr O P Bakshi	
Minority Ethnic Carers of Older People Project	Sharmila Sockhoe Eliza Leung		Ms Arifa Aziz Mrs Sharif Ms Rose Tibi
Shanti Bhavan	Kavita Agarwal	Mr J R Chadha	Mrs Leela Sethi

**Speakers, Staff and Interpreters**

Sir Stewart Sutherland, Chairman, Royal Commission on Long Term Care for the Elderly  
 Alan Davey, Secretary, Royal Commission on Long Term Care for the Elderly  
 Marion Morton, Councillor, Chair of Race Equality Forum, Edinburgh City Council  
 Naina Patel, Mick Convoy, Suzanne Munday, Jeanice Callendar, Kiran Duggal and Maqsood Ahmad

**Also invited**

Leith Sikh Community Group; Multicultural Elderly Day Care Centre; Pius Nyiam Africa Centre, Scotland; Milan Senior Welfare Council; San Jai Chinese Project; Mental Health Framework Project; and Wing Hong

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**And Edinburgh City Council, Leeds City Council and staff at the CRE, London for hosting the Royal Commission Seminars.**

Note: We recognise that, in the process of seminar attendance and delegate changes, some names of delegates may have been omitted and/or misspelt.

