A Conference Report
on
Delivering Quality
Minority Ethnic Elders’
Health and Social Care
in
Europe

4th October 2005
Queen Elizabeth II Conference Centre, LONDON
1) Introduction – Age and the Human Condition

“When you are young you will dress yourself and go where you want to go. When you are old someone else will dress you and take you where you don’t want to go.” The Bible.

After two thousand years, this depiction of old age echoed by PRIAE’s patron, Dr Chai Patel, in his conference address, still has the power to stop you in your tracks. It’s an image that conjures up, with graphic honesty, the truth of what it is to grow old and dependent, reliant on other people for even your most basic needs and comfort.

The population of Europe is growing older. Yet, even as we age there is, perversely, a tendency to marginalise elderly people, particularly those who combine infirmity with old age. As Dr Patel observed in his presentation, today we pay “a lot of lip service to age and to wisdom.” Yet, when the talking is done, the elderly are a section of our society whose needs are frequently forgotten, a group which has often “to get very shrill to get the attention of those who can make a difference.”

One of the core goals of PRIAE — a goal highlighted by PRIAE’s Chair, Lord Ouseley in his introductory remarks, and constantly returned to by speakers at the conference — is to allow the real life experiences of black and minority ethnic elders to be heard by policy makers, and in so doing change their experience of old age for the better.

2) Making Quality of Care a Reality for All

“All is not well in health for the majority of the older population. But if you are from a minority ethnic background, increased poverty, ill health, practical difficulties in gaining access to appropriate health and social care and existence of relatively poor minority age organisations, prevent the possible experience of a normal and decent life in old age.” Professor Naina Patel, director of PRIAE.

Enabling older people to get more out of life is all about helping people gain access to the things that make for a decent quality of life. Today, we recognise that the ingredients of a fulfilled old age include experiences that encourage people to remain active and engaged with the wider world — recreation, friendship-networks and opportunities to learn — as well as services, such as health and personal care that cater for basic needs.

It’s an aspirational view of old age to which, encouragingly, policy makers in the UK are — if judged by their words — fully signed up. As Mark Heholt, head of the Department for Work and Pension’s Ageing Society Division, said: “We need to talk more about aspirations. It’s not about surviving, it’s about enjoying life.”

But there’s a problem. The idealised old age to which we aspire is so far removed from the day-to-day reality of people’s lives that it barely looks credible. Elderly people who are marginalised, by virtue of their ethnicity or culture, know this from personal experience. However, the predicament of this section of society has rarely had the attention it demands, partly because the statistical evidence needed to back up individual case histories and to guide public policy has not been there.
Now, thanks to the pan-European Minority Ethnic Care (MEC) Research\(^1\) led by PRIAE, policy makers are able to quantify the real-life experiences of BME Elders and start to build services that respect the user’s culture. What is more, there is also the hope that in developing services that take account of people’s cultural needs, service providers will learn a new approach to care — one that attaches a lot more importance to respecting the individuality of elderly service users and the preferences and sensitivities that they have developed over the course of an entire lifetime. This, ultimately, is a lesson in humanity which has the potential to benefit everyone, whether from the mainstream population or a minority community.

2.1 Defining Quality
At the centre of the debate around quality care for older people is the question of what is meant by quality. Historically, what governments have meant is making centrally provided services of a consistent standard available to all. This one-size-fits-all approach has let down many elderly people, but most systematically it has failed those with culturally distinct needs, such as ethnic minorities.

In Britain there is now a commitment in government to move away from the straight-jacketing effects of the old take-it-or-leave-it model of service provision. This point was emphasised repeatedly at the conference, especially by Stephen Timms, minister of state for work and pensions, who spoke about “a new approach to care,” epitomised by the introduction of individual budgets, which will allow service users to “buy and put together care packages to meet their own needs and aspirations.” In particular, Mr Timms described individual budgets as having “a lot of potential to benefit BME elders, who will for the first time be able to shape the care services they receive, rather than having to put up with whatever services are provided.”

But allowing people greater choice isn’t simply a matter of “putting the service user in the driving seat.” As a representative of Age Concern pointed out, owning a budget is meaningless if the market isn’t supplying services to meet your needs. For many elderly people it is at this point, the point-of-purchase, that the promise of choice and personalised care melts away.

2.2 The Legacy of Inadequate Provision
The reasons for the continuing absence of choice in care services for elderly minorities can only be understood in context. Historically, statutory providers have not developed culturally appropriate services because they have not recognised, or been forced by the courts to recognise, that they have a duty to make provision for groups with specific cultural needs. Minority voluntary organisations, for their part, have lacked the resources to do more than offer basic support, such as lunch clubs and day-care.

In this sense it can be argued that ethnic minority communities have been doubly penalised — persistently ignored by mainstream services, their voluntary bodies have

\(^1\) MEC Minority Elderly Care is a PRIAE concept and designed and submitted for funding in year 2000, led by PRIAE under the EC 5\(^{th}\) Framework Research Programme, which involved 10 European countries and created 12 full time three year research posts. PRIAE with its European partners launched the results at the European Parliament in December 2004 and this conference under the UK Presidency launched the UK report in October 2005 following a Leeds Launch in April 2005. See www.priae.org to download the two summary briefings
also been denied the core funding to develop culturally appropriate care to mainstream standards. Inevitably, it is the most marginalised and dependent members of society who have been, and are still, suffering as a consequence of this failure in provision. Witness the total isolation, described to the conference, of an elderly man, who speaks only Chinese, placed in a mainstream care home where none of the staff or other residents speak Chinese.

So how, given the commitment to change amongst policy makers and service providers, can the care system be made to work better? Here, in summary form, are some tentative themes and conclusions drawn out from the discussions at the conference.

3) Strategic Pathways

3.1 Capacity Building in the Voluntary Sector

“Ideally social services should be offering services for ethnic minority elders, but in the absence of that happening voluntary organisations should be supported with mainstream core funding from the centre.” Jyoti Hazra, founder and director Bharatiya Ashram, Dundee.

The UK government has made it clear that it wants to bring about “person-centred” care and that BME voluntary organisations will play a pivotal role in designing and delivering services to elderly people with particular cultural needs. The vast majority of BME organisations, as the MEC research demonstrated, want to offer a fuller range of services to their clients. These organisations lack neither the will nor the commitment to expand, but simply access to adequate and sustained core funding. As one contributor commented, “the voluntary sector is littered with projects that are funded for one or two years. This raises people’s expectations, but then the funding runs out.”

BME voluntary groups came into being to compensate for the lack of culturally appropriate care in mainstream provision. Since the elderly people who depend upon their work have no other means of getting care that is appropriate to their needs, it is only right, and in policy terms efficient, that BME organisations should be granted core funding to build up their services to mainstream standards.

3.2 Partnerships

“We must try to get contracts that work for the voluntary sector as well as the NHS, because in the past it has seemed to be somewhat one-sided.” Jo Webber, policy manager the NHS Confederation.

The prospect of a market emerging in care provision, as a result of the government’s modernisation programme, offers a chance for voluntary organisations to offer culturally appropriate care to local users on behalf of social services. This was one of the key messages articulated by the representatives of central and local government who painted a picture of a world in which private, public and voluntary care providers will work in partnership with each other to make limited resources stretch further.
In theory the new vehicles of individual budgets offer the opportunity for BME voluntary organisations to formalise and expand their services. Once again, however, this will only happen if commissioning bodies tackle the core issue of offering contracts that allow voluntary partners a reasonable planning horizon.

3.3) Personalising Mainstream Care

Entrepreneurial voluntary services operating on shoestring budgets are already making a big difference to the lives of elderly people; given adequate support they will make an even greater contribution in the future. However, to expect the voluntary sector to take the lead in providing care to ethnic minority elders is fundamentally to miss the point. Legal responsibility for ensuring that elderly people have access to culturally appropriate care lies not with voluntary groups, but with statutory providers whose duty it is to research people’s needs and provide, or buy in, services to meet local requirements. This is a basic principle that needs to be unequivocally stated by government and effectively enforced. But what else needs to happen, on the ground, to improve people’s real-life experience of health and social care? Here, the MEC research has important insights to contribute.

In the UK, the vast majority (80 per cent according to the MEC research) of professionals working in health and social services, agree that BME elders face particular problems in accessing care. This recognition of the barriers that minority ethnic elders must overcome to benefit from public services represents progress of sorts, even if the solutions aren’t always in place. The UK consensus serves also to highlight a gap that is opening up between the UK and other European countries, such as Spain and Switzerland, where there is much less agreement on the need to supply services that respect the user’s cultural identity.

Yet even in the UK, where the moral argument appears to have been won, it is still demonstrably the case that ethnic minority elders often feel let down, even alienated, by their experience of mainstream provision. The crux of the matter is the question of what culturally appropriate care consists of in practice, and who defines its scope — the service user or the statutory provider? As the MEC study points out, statutory providers should, as a minimum, offer translation services and food that minorities will be familiar with and able to enjoy. But on the top of doing the obvious things, care givers also need to have clear policies on how to accommodate the cultural sensitivities of their clients, for example, on issues to do with body-care and separation of men and women; issues “which, although not perceived by the service provider as important, may be very important to some of their service-users.”

4) Way Forward

The following recommendations are based on the policy debate that took place at the conference.

4.1 Training

Most health and social care professionals are naturally sympathetic; most acknowledge the importance of “caring for the whole person.” But as PRIAE trustee Liam Hughes remarked, under the pressure of everyday work “sensitivity to the
individual,” and with it sight of the patient’s whole history and culture, can quickly disappear.

To change people’s everyday experience of healthcare requires a new set of medical priorities: one where respecting an individual’s cultural expectations and life-history is seen not as the icing on the cake, but as much a part of quality care as giving the right medicine or nutrition. The most effective way to bring about such a shift in outlook is to make the principle of providing culturally sensitive care a core element of the undergraduate training of all doctors and nurses.

4.2 Recruitment

Building effective cultural understanding and language skills in health and care services demands a culturally diverse workforce. Recruitment advertising targeted at ethnic media and programmes to make ethnic minority career-seekers aware of opportunities in the caring professions have the potential to help in this respect.

4.3 Dispelling Stereotypes and Developing Evidence-based Policy

“Services must be designed to reflect the diversity of the population, not some [mythical] average population.” Craig Muir, head of older people’s services, Department of Health.

4.3.1. Elderly Males — a Forgotten Minority

The MEC research highlighted particular shortcomings in the provision of culturally appropriate services for elderly men. The reason for this deficit isn’t fully understood, but there is a suggestion that when authorities develop services they do so from a “female perspective,” perhaps reflecting the fact that on average (though this is not true of some ethnic communities and localities) elderly women outnumber men.

This dearth of services catering to the needs of elderly men is an issue that policy makers and statutory providers need to pick up from the MEC research. The fact that elderly males from minority communities have a higher incidence of emotional problems than elderly women adds weight to this recommendation.

4.3.2 Health Inequalities

The MEC survey also highlighted the incidence of health inequalities in Britain. In particular, the research contains new data on the exceptionally high rates of heart disease and diabetes found in some minority communities, such as South Asians and African-Caribbeans.

Publicly-funded research is now needed to find out why these differences exist, and still more importantly, how they can be prevented. At a local level, health authorities need to look at how health advice is communicated to elderly people from ethnic minorities and whether more could be done to adapt programmes, such as the NHS’s expert patient scheme, to help BME elders with chronic conditions manage their health more effectively.
4.4 Representation of Minority Views

Involving BME service users in the design and piloting of health and social care programmes, such as the NHS’s expert-patient scheme, is absolutely central to making “person-centred” care a reality. But, just as elderly people from ethnic minorities have problems accessing care, so they also face barriers in making their views known to policy-makers. Development of BME advocates, closer collaboration with voluntary organisations and a reappraisal of where, when, and in what languages patient forums are held, are all actions that have the potential to boost BME participation in service development and which statutory authorities should explore.

4.5 Joined Up Service Provision and Legal Empowerment

The introduction of individual budgets has been presented as an opportunity for BME elders to “Shape the care that they receive rather than having to put up with whatever services are provided.” But the desired market in services will not emerge spontaneously. As things stand local authorities and service providers have no incentive to collaborate with each other or to trade resources to make it possible for, say, elderly residents to travel between authorities to benefit from specialist services. For the government’s reforms in respect of individual budgets and public services modernisation to take their intended effect it is clear that statutory providers must be given incentives to pool resources and to work collaboratively to achieve the best outcomes for their residents and patients. Likewise, statutory providers that fail to make appropriate provision for minorities should be held accountable for their inaction and, where necessary, penalised.

In the absence of effective rewards and legal clarity on where responsibility lies, we know what to expect. Elderly people will go on suffering the indignity of being shunted between health and social services, or experience the frustration of being told that they are not eligible for care that is appropriate to their needs, simply because they live in the wrong borough. Where this is the case, the only remaining option is, regrettably, for service users and their advocates to fight for their entitlements. As Lord Dholakia expressed it in his summing up: to inform themselves “about their legal rights as rate payers and tax payers and confront [their] local authority.”

5. Conclusion

Providing care that respects people’s preferences and culture, whatever their age or ethnicity, is, or at least should be, what delivering quality services is all about. Politicians talk readily about “personalising” care, but what exactly they mean by this term is not always clear. Is the concept of “person-centred care” something that we want everyone to share in, or, when the chips are down, are there still some in society — the most dependent and vulnerable — whose needs and preferences we would prefer to forget? How we answer this question says a lot about our society and how far, or how little, we have travelled in the past two thousand years.

With thanks to Alicia Clegg, Journalist, for writing this conference report and to Craig Muir, Department of Health for funding the conference and related items. And to all our speakers for their full contribution and to the delegates who attended and took part to make the conference a successful event. www.priae.org
9.00 Registration, Refreshments and Conference Opening

9.30 Welcome from the Chair
Lord Ouseley, PRIAE Chair

9.40 The importance of quality care
Dr Chai Patel, CBE, FRCP, PRIAE Patron

9.50 Opening Keynote Speech: Ageing with Care and Quality of Life
Mr Stephen Timms MP, Minister of State for Work and Pensions

10.10 Discussion

10.30 Minority Elderly Care (MEC) Research Presentations
UK: Dr Kathryn Watson, PRIAE
Spain: Dr María Angustias Martín Quirós, Plan Excel S.L. Spain
Switzerland: Professor Claudio Bolzman/Dr Marie Vial, IES
Introduced and concluded with proposals: Professor Naina Patel, PRIAE

12.10 Discussion

12.30 Lunch

13.40 Delivering quality: implementing MEC findings and challenges
How does the MEC research inform policy, strategy and change Panelists?
- Claude Moraes, MEP for London, President of the Anti-Racism and Diversity Intergroup
- Dr Rekha Elaswarapu, Strategy Development Manager, Healthcare Commission
- Jo Webber, Policy Manager, The NHS Confederation
- Cllr David Rogers OBE, Chair, Community Well-being Board, Local Government Association
- Liam Hughes, Chief Executive E.Leeds PCT, PRIAE Trustee
- Mark Heholt, Head of Ageing Society Division, Department for Work and Pensions

Panel Chaired by Joel Kibazo, Director of Communications & Public Health, Commonwealth Secretariat

15.15 Refreshments

15.30 MEC research application from experience - practice perspectives:
- Commissioner’s perspectives
  Paramjit Singh, Commissioning Manager, Brent Teaching Primary Care Trust
- Equalities perspectives
  Farkhanda Chaudhry, Development Officer (Equalities), East Renfrewshire Council
- Manager’s perspectives
  Samantha Greenidge, Service Development Manager, Croydon Council
- Elders' and Advocates’ perspectives
  Mrs Shu Pao Lim MBE, Founder & Chair of Great Wall Society
  Mr Jyoti Hazra, Founder & Director Bharatiya Ashram, Dundee

Chaired by Professor Sashidharan, PRIAE Trustee

16.10 Concluding Keynote Speech: Delivering appropriate and effective services
Craig Muir, Head of Older People’s Services, Department of Health

Chaired by Lord Dholakia, PRIAE Trustee with concluding remarks

17.00 Close of Conference
Evaluation Comments

Additional Comments

- ‘Liked the welcoming band!’
- ‘Nice food at lunchtime’
- ‘The music was a fantastic way to start the conference. A positive day with lots of information to take away and implement’

- ‘Would be great to establish some think tanks / learning sets to work together with this research to inform service improvement and design (EG Joint Working)’
- ‘It has been a valuable, interesting day – thank you’
- ‘Very informative conference’
- ‘Good central location. Important to be part of the wide research that will affect practice across the EU’
- ‘Conference content was interesting and thought provoking, very enjoyable’
- ‘Really interesting material which was thought provoking but too much delivery from power point with insufficient opportunity for interaction’

- ‘The morning session was too long without a break’
- ‘Conference had a very early start for those travelling and unable to stay overnight’
- Far too much presentation. The content and research often good, it is a fantastic evidence base. What a shame we couldn’t have spent time looking at it together and debating the implications for commissioning and delivery of services and involving older people in developing commissioning strategies’
- ‘Found all information informative but statistical data, difficult to focus on’

- ‘A good and enjoyable conference, thanks to all of you!’
- ‘Keep up the good work, now is the time to make it happen’
- ‘Excellent event, a real boost’
- ‘The conference was very enjoyable and lots of learning. All the panels were very good, the structure of the day was excellent. Lunch would have been more enjoyable if we were able to sit down’
- ‘Great networking opportunity’

Any Comments on PRIAE’s work and Approaches

- ‘The work seems good and the academic basis is sound and useful’
- ‘Excellent piece of research that will be useful specifically to support the management of change required to provide a patient centred service. Need to learn more about the work, will visit the website’
- ‘First time I have come across you – I will be paying close attention from now on’
- ‘We need more links and feedback as very few people in normal life know about PRIAE. More publicity required’
- ‘Happy to be contacted in terms of providing specialised services to Asian elders’
- ‘Excellent approach. I hope the research will enable to make the change so badly needed by our policy makers’
- ‘Excellent pioneer work’
- ‘This is a very good example of sound, robust research into this area of work’
- ‘The research data is an excellent achievement. Now no decision makers will say ‘no evidence available’’ Keep it up’
- ‘Look forward to a year forward report detailing what has changed since the research paper as well as a commitment made by health and social care providers’
- ‘I knew little about it before, so a real learning curve – clearly a sterling organisation’
DELEGATE LIST

Ms Efua Taylor                        African & Caribbean Elders
Miss Shazia Butt                     Adult care Services-Hertfordshire
Ms Neema Mandalia                   AFIYA Trust
Ms Manuette Patel                   Age Concern England
Mrs Lulyn Tavares                    Age Concern England
Mr Malik Fayaz                        Age Concern Herefordshire & Worcestershire
Mr Jorge Lagos                         Age Concern Waltham Forest
Mrs Sheena Dunbar                        Age Concern Waltham Forest
Mr Joe Blackledge                         Alzheimer's Society
Mrs Jane Ashcroft                                Anchor Trust
Ms Judith Clark                           Ashley Homes
Mrs Gopalbhai Popat                   Asian Foundation for Help
Mr Dial Sharma                                   Asian Foundation for Help
Mr Mahesh Amin                                  Asian People's Disability Alliance
Mr Ashok Ghose                                   Asian People's Disability Alliance
Mr Kanubhau Patel                                  Asian People's Disability Alliance
Miss Susan Price                             Association Of London Government
Ms Sangita Pandya                                  Barnet Asian Older People’s Association
Mrs Val Houlton                              Bexhill and Rother Primary care Trust
Ms Patricia Harris                                   BGOP
Mr Jyoti Hazra                                          Bharatiya Ashram
Ms Sangita Pandya                                   BMCC
Mr Paramjit Singh                             Brent PCT
Mrs Aisha Khan                                          Brent Teaching P.C.T.
Mrs Jasbir Mungur                                 Bury Adult Care Services
Mrs Bridie Brennan                                Camden Elderly Irish Network
Mrs GNA Pursey                                    Camden Elderly Irish Network
Ms Jenny Lam                                            Chinese National Healthy Living Centre
Ms Lynne Gillett                                         City Parochial Foundation
Mr Joel Kibazo                                          Commonwealth Secretariat
Dr Harshad Mistry                                Confederation of Indian Organisations Uk
Ms Samantha Greenidge                              Croydon Council
Mr Andy Barker                                             Department of Health
Mr Jim Fowles                                          Department of Health
Ms Kate Hardy                                           Department of Health
Mr Craig Muir                                           Department of Health
Ms Lynne Simpson                                     Department of Health
Mr Raymond Warbuton                                   Department of Health
Ms Annette Davis                                       Department of Health
Mr Fahd Khair                                           Department of Health
Ms Val Rowlands                                        Devon Racial Equality Council
Ms Sam Balkwill                                        Disability Rights Commission
Ms Farkhanda Chaudhry                                E Renfrewshire Council
Mr Liam Hughes                                   East Leeds PCT / PRIAE Trustee
Mr Tim Bishop                                                 East London & City Mental Health NHS Trust
Ms Jessie McArthur                                      East Sussex Council
Ms Claire Debenham                                     East Sussex Council
Mrs Ramesh Verma                                         EKTA
Ms Helen Lindars                                             EOC
Mr Claude Moraes MEP                                 European Parliament
Mrs Shu Pao Lim MBE                                     Great Wall Society
Ms Carmen White                                         Hamac Housing Association
Ms Kalyani Gandhi                                      Hanover Housing Association
Ms Kate Anderson                                        Health And Social Care Information Centre
Mr Simon Archer                                        Health And Social Care Information Centre
Dr Rekha Elaswarapu                                    Healthcare Commission
Ms Heather Richardson                                    Help The Hospices
Mrs Rakshita Patel                                         Home Office
Lauren Webb                                               ICAS
Professor Claudio Bolzman                           IES, Switzerland
Ms Marie Vial                                             IES, Switzerland
Ms Ayesha Saeed                                             Improvement & Development Agency (IDEA)
Dr Freda Mold                                           King's College London
ABOUT PRIAE

PRIAE is a national and international charitable Institute working to improve the situation of older people from black and minority ethnic (BME) backgrounds in the UK and across Europe, in a range of areas including; pensions, employment, health, social care, housing, and quality of life/citizenship. The Institute was established in 1998 to provide a concentrated and clear voice on issues that BME elders face. To support and take action in research, information, service developments where there are significant gaps and to use this effectively to influence and contribute to policy making and its implementation, engaging BME elders and organisations. Such an investment will help to improve quality of life of BME elders and strengthen BME age sector through support to BME organisations as an ‘umbrella body’.

PRIAE works on
- Income, pensions and employment
- Health, Social Care, Housing
- Citizenship and Quality of Life

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