

'Let's move on'

‘Let’s move on’

Black and Minority Ethnic older people’s views on research findings

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Contents

1 Introduction	1
Background to the issues	2
2 The processes of the consultation	3
3 A brief history of research on black older people to 2001	5
Demography	5
Household composition	6
Health and social care needs	6
Poverty and housing	8
Knowledge and use of services	9
Who cares?	10
Conclusion	11
4 Response of older people to findings	12
Other key themes	12
5 Discussion	17
Involving black older people	18
Some wider national issues	19
References	21

1 Introduction

This project is part of a series for the Joseph Rowntree Foundation's Older People Programme. The programme as a whole is defined by a steering group of older people, supported by officers, researchers and policy analysts. Steering group members were keen that the programme should reflect the ethnic and cultural diversity of older people themselves. The steering group has representation from different communities and different parts of the United Kingdom. Nevertheless, steering group members felt it was very important that an agenda for future work *about* older people from Black and Minority Ethnic communities should be set *by* older people from Black and Minority Ethnic communities. Therefore the Foundation's Race Equality Advisers (REU – formerly the Race Equality Unit at the National Institute for Social Work) organised a series of meetings with black older people in Leeds, Bristol and London.

- The report that follows represents the views of black older people. It is not (and is not intended to be) a comprehensive review of all research work (past and current) about the lives of older people from Black and Minority Ethnic communities.
- Their views are partly comments on summaries of key themes in research presented by REU at the events. A summary of the key findings is presented in Chapter 3.
- However, it was quite surprising that many of the older people in the different areas were already familiar with the experience of being researched over many years – sometimes for national or academic studies, sometimes for local or regional service development plans. They had quite firm views, both on the validity of topics for research and on the usefulness and meaning of research in their own lives.

It is likely that their comments will provoke discussion or disagreement. The groups are not (and do not claim to be) experts in research methods or in the detail of any particular studies. However, it has been quite sobering for the authors of this report to contrast the views of older people (wanting to move on from, as they see it, research for its own sake) with parallel discussions that the authors have been involved in with academics (who wanted to do yet more in-depth analysis of specific areas, while also recognising that research to date seemed to have made little impact in the issues of race equality).

Background to the issues

At the time of the consultation events, the team noted that the numbers of older people from Black and Minority Ethnic communities in the UK were rising rapidly, from about 60,000 in 1981 to around 360,000 in 2001/02.

Even though the numbers had been initially quite small, this is not a new area of investigation. The research on Black and Minority Ethnic older people is remarkable because of the sheer quantity of material in comparison to other areas of social care and ethnicity. In fact, black older people at the three consultations said that their personal experiences were of having been ‘researched to death’ for at least the past 15 years, and the frustration they felt was that new research was often asking exactly the same questions that were being asked 15 years ago by a previous generation of researchers. Adding to their frustration was that the research that had been conducted had not seemed to have helped bring about a great deal of change in practice.

The report that follows reflects the discussions that took place at these three meetings. The consultations were an attempt to develop an informed dialogue, with information being shared with Black and Minority Ethnic older people as well as being gained from them.

Probably the central finding of this work was that black older people did not want more research that did not contribute to change in their circumstances. Also they did not want more one-off consultations.

Foundation staff and their advisers said that they would try to live up to a vision of older people being involved in saying what the priorities were, getting feedback on what was happening, helping to shape new directions and helping to make the final results useful (both in their own areas and nationally). This report should therefore be seen as the start of a journey for the Older People Programme, not its end.

2 The processes of the consultation

The initial consultations were taken forward during June and July of 2001 using a combination of methods, including:

1. a short written paper on some of the messages of research
2. three meetings around the country (Leeds, Bristol, London)
3. time to explore and question the results of existing studies (including discussions facilitated in community languages)
4. a written account of each meeting
5. feedback on the outcome of the consultation events
6. longer-term involvement in the assessment and review of the work supported around older people from Black and Minority Ethnic communities.

Black and Minority Ethnic older people took part in workshops and discussions. These discussions provided an opportunity for them to review existing research on Black and Minority Ethnic older people. The discussion allowed them to highlight issues that affected them and also look at how future research or development work might be taken forward.

Contacting Black and Minority Ethnic older people took place through a range of Black and Minority Ethnic-led and other organisations working with Black and Minority Ethnic older people. This included voluntary, self-help and religious organisations as well as statutory providers. Particular attempts were made to contact newly arrived communities, such as the Somali community, through local Somali community organisations. We also tried to make sure we involved women as well as men.

For each of the consultations an average of 35 ethnic elders attended, with representatives from the African, Bangladeshi, Caribbean, Chinese, Indian and Pakistani communities. Interpreters were available to translate into the respective languages for the different communities who attended. The day was planned with a mixture of working sessions and informal, relaxed breaks. Food was an important ingredient of the day – good food, not just curled-up sandwiches.

The day started with a presentation on the main findings from existing research on the experience of Black and Minority Ethnic older people (summarised in Chapter 3). Discussion took place in smaller groups.

Within the smaller groups there was an average of five to six in a group. The facilitators revisited the main issues from existing studies and discussed how the experiences of the older people differed from or was the same as the findings. These discussions also allowed those older people to highlight their own experiences and identify issues where there appeared to be gaps.

During the afternoon the discussions focused on any further areas of research and development work which would be important for older people themselves and what they hoped that future work might lead to in practice. These summary recommendations are presented in Chapter 4.

The consultations during 2001 were then followed up with a meeting across the different groups (Leeds, London and Bristol) at the Leeds Chinese Community Association in July 2002. The draft of the present report was presented to the meeting and there was discussion about how the work might proceed in practice.

Funding proposals were taken to the Social Care and Disability Committee in October 2002 and a proposal was supported which would work with the Leeds Chinese Community Association, the Gloucestershire African Caribbean Elders Association, SubCo in Newham and three other Black and Minority Ethnic community organisations. The new project would look at developing lessons of good practice from within minority community organisations.

The new projects are starting during 2003 and older people from Black and Minority Ethnic communities will have an important role, both in the projects themselves and in the Foundation’s advisory groups, in overseeing progress and conclusions from the work.

3 A brief history of research on black older people to 2001 (summary of presentation to the groups)

The research on Black and Minority Ethnic older people is remarkable because of the sheer quantity of material in comparison to other areas of social care and black communities. Much of this is small-scale local studies concerned in the main with the policy and practice implications for service development rather than the incidence and prevalence of needs. However, these studies do allow us to build a picture of the key issues affecting black older people. A review of literature suggests the following.

- Both the numbers and proportion of older people from Black and Minority Ethnic groups within the population are rising and will continue to rise for the foreseeable future.
- Black and Minority Ethnic older people have considerable health and social care needs and these needs occur in a comparatively younger group of black older people than white older people.
- Despite the existence of considerable health and social care needs, black older people's knowledge and use of services are low compared to white older people.
- There is some evidence that Black and Minority Ethnic older people are more likely to face a greater level of poverty and have lower levels of income than white older people.
- Black and Minority Ethnic older people are more likely to live in poorer quality housing which lacks basic amenities and this may impact on their health.
- The notion that the extended family will look after their 'elders' may be a myth and certainly masks the level of true need.

Much of this research describes the diversity of experience between different minority ethnic communities and often it also describes any difference in experience between men and women. However, the experience of the Chinese and African (particularly the recently arrived) communities is dealt with by only a few studies; also attention to how religion impacts on service receives limited attention.

Demography

Though the proportion of black older people compared to white older people is small, it is clear that both the numbers and the proportion of elderly people from Black and

Minority Ethnic groups within the population are rising. Owen (1993) details the changes between 1981 and 1991 of various age cohorts and suggests that while the number of New Commonwealth and Pakistani people who are between 45 and pensionable age has grown by 35 per cent, the largest percentage growth has been in those people of pensionable age – 168.6 per cent (from 61,200 in 1981 to 164,306 in 1991). The 2001/02 Labour Force Survey suggests that these figures have risen to over 360,000 people (White, 2002).

Furthermore, unlike for white older people, the census suggests equal numbers of male and female Black and Minority Ethnic older people.

Household composition

The number of households with pensioners amongst the Caribbean community is 7.2 per cent, approximately 15,500 households. For the Chinese community it is 3.7 per cent, about 1,800 households. For the Indian community the figure is 2.6 per cent, about 8,100 households, with a smaller number amongst African, Pakistani and Bangladeshi communities.

Lone pensioner households in the white community account for a larger percentage of households than is the case for lone pensioners in any Black and Minority Ethnic group: 15.6 per cent as opposed to 2.8 per cent. In terms of individual minority ethnic communities, the Caribbean community has the largest number of lone pensioner households (5.5 per cent, around 11,600 households). Asian older people have been shown to be more likely to live in larger households with relatives; this is especially the case for groups such as Pakistani or Bangladeshi families.

Health and social care needs

A growing body of research evidence highlights the health and social care experience of older black people (Bhalla and Blakemore, 1981; Farrah, 1986; Fenton, 1987; Ebrahim *et al.*, 1991; Butt and Mirza, 1996; Yu, 2000; Raynes *et al.*, 2001). This small-scale work is now being confirmed by secondary analysis of national data sets (Modood *et al.*, 1997; Evandrou, 2000).

In the 1980s Farrah found that although two-thirds of his sample of black older people were aged between 59 and 69 years, 89 per cent reported poor eyesight, 12 per cent hearing difficulties and 28 per cent hearing problems, 22 per cent were suffering from diabetes, 39 per cent from high blood pressure and 51 per cent with arthritis. Over a third of those reporting health problems also said that their activities

were restricted because of ill health, in particular mobility. At the beginning of the 1990s Ebrahim *et al.* (1991) found the incidence of chronic illness among Gujaratis aged 54 and over to be generally higher than amongst whites of a similar age. It was also found that the onset of difficulties in daily living may occur at an earlier age in this population.

The Fourth National Survey of Ethnic Minorities (Modood *et al.*, 1997) found a higher incidence of ill health amongst minority ethnic communities, including high levels of long-standing illness and evidence of mobility impairment as a result of health problems. In addition, compared to the white community, it suggested:

- higher rates of coronary heart disease for Pakistanis and Bangladeshis
- higher levels of hypertension amongst the Caribbean population
- higher rates of diabetes for all black communities.

In putting together six years of data from the General Household Survey Evandrou (2000) shows that older people from ethnic minorities are more likely to report poor health 'over the last year' and more likely to report that an illness or injury has restricted their 'activity' in the last two weeks. While there are some differences between men and women it is nevertheless a consistent pattern in the evidence from the General Household Survey.

There is some evidence that this experience of physical ill health may be accompanied by a particular risk of suffering from dementia and depression. Caribbean older people are likely to suffer from higher rates of multi-infarct dementia, and the hostile environment that these older people live in may well lead to increased experience of depression (McCracken *et al.*, 1997). Abas (1996) also identifies the stereotype that Black and Minority Ethnic older people reside within a supportive extended family network and therefore don't have the need for services that white older people do as a reason why so little has been written about depression and these communities.

It is the case that depression is more widespread than dementia and can have a great impact on the quality of life of Black and Minority Ethnic older people. Yet there is little information on its prevalence or their experience of depression. However, in one study of dementia and depression amongst Black and Minority Ethnic older people in Liverpool McCracken *et al.* (1997) found that levels of depression were comparable with those of their white counterparts, although slightly higher amongst the category of black African. The authors further suggest that a lack of social

contact with relatives was associated more with depression among older black people than among the white population. Issues of isolation, depression and mental health problems among Chinese older people are also important (Yu, 2000) and contrast with the comparatively robust physical health of other older people in the same community (Raynes *et al.*, 2001).

Both Abas (1996) and Rait and Burns (1997) suggest there is value in professionals being ready to acknowledge and discuss a range of factors which impact on the way that the older person is feeling. Rait and Burns point out that the effect of migration and subsequent loss of homeland, culture, language and family should be taken into account, and further note that South Asians in their study tended to connect their psychological distress to social problems such as housing, unemployment, racism or isolation. Abas also identified racism as an important factor, arguing that it is essential to look at black older people’s mental health in the context of unmet need and wider requirements for care.

In terms of dementia, a study on this area by Patel *et al.* (1998) raises several issues for practitioners working with black older people who may be experiencing dementia. First, the evidence from this study suggested high levels of family referrals compared to referrals from GPs and social workers to organisations working in this field, and the authors suggest that this could be a sign of the family being unable to cope and needing some help. Second, there is the issue of communication. This involved both being able to communicate in the older person’s mother tongue and the methods used to diagnose dementia.

Poverty and housing

These greater levels of frailty and ill health experienced by Black and Minority Ethnic older people are accompanied by comparatively worse economic and housing conditions. While ‘pensioners’ as a group tend to be poorer than other people in Britain, the evidence demonstrates that Black and Minority Ethnic older people are likely to have a lower income than white older people (Berthoud, 1998; Evandrou, 2000). Berthoud (1998) showed that:

- The total average family income for white pensioners was higher (over £180 per week) compared to Caribbean, Indian, Pakistani and Bangladeshi pensioner families (between £140 and £150 per week).
- White pensioner families were more likely to receive state earnings related pension than Indian and Pakistani/Bangladeshi pensioners.

- While Caribbean pensioner families were as likely as white pensioner families to receive state earnings related pensions the amount they received was less.
- White pensioner families were also more likely to receive occupational pensions than any of the Black and Minority Ethnic communities.
- Pakistani/Bangladeshi, Caribbean and Indian pensioner families were more likely to be dependent on means-tested benefits than their white counterparts.

In terms of housing it appears that these older people own the worst type of accommodation, often without the benefit of basic amenities. The most recent English Housing Condition Survey shows that within the owner-occupied sector different ethnic groups occupy different types of housing. For example, households of Asian origin were more likely to own older dwellings – 41 per cent were living in pre-1919 terraced houses compared with 14 per cent of white households, and there was a greater likelihood of living in accommodation with no central heating (Department of the Environment, 1991). Evandrou (2000), in her analysis of the General Household Survey, shows a similar picture and also details higher rates of overcrowding for Indian, Pakistani and Bangladeshi older people.

Knowledge and use of services

Much of the available literature demonstrates lack of knowledge and underuse of social care services by black older people irrespective of age and disability. For example, a survey of black older people in Coventry by Lewando-Hundt and Grant (1987), looking at their present and future needs, found that black older people know very little about the social services available to them.

The picture in relation to health services is similar. For example, despite the greater use of GPs who might have been expected to be important sources of referral to other services, there is evidence to show a low level of contact with district nurses and health visitors among black older people. When we go beyond primary care and consider out-patient clinics and residential facilities, the picture is no different. Blakemore (1982), for example, found that despite a high incidence of GP consultations, 99 per cent of Asian and 97 per cent of Afro-Caribbean elderly people had never seen a health visitor, while 99 per cent and 92 per cent respectively had never seen a district nurse.

Evidence from the 1990s suggests that the inappropriateness or lack of services for Black and Minority Ethnic older people (Murray and Brown, 1998) continues to be a

problem, including some evidence of services being offered and rejected (Butt, 1994). There is clear evidence that a significant number of the services that now exist did not exist before 1990 (sheltered housing in Newham, specific home care services in Camden, support for disabled adults in Leamington Spa). Furthermore, these services support a more diverse group of people (the Chinese in Liverpool, Asians in Leicester, Caribbeans in Bristol), and they also exist throughout the country (in Southampton, Newcastle, High Wycombe) (Butt and Box, 1997). Nevertheless, the first ever Social Services Inspectorate inspection of community care services for black older people showed that most departments’ response was still inadequate (Murray and Brown, 1998).

Who cares?

However, while these studies do suggest that multi-generational households may still be the norm for most black communities, we should not assume that they are either a source of support for Black and Minority Ethnic older people or able to provide for the care needs of these people (Fenton, 1987). The evidence appears to suggest containment rather than care and certainly undermines the old adage that they look after their own (Murray and Brown, 1998; Yu, 2000).

Studies document the lack of support, isolation and loneliness felt by Black and Minority Ethnic older people. For example, Barker (1984) noted that though Asian older people were more likely to live in large households it did not mean that Asian older people were always housed well or actively involved in household life. Turnbull (1985) notes that even within the extended family setting there was often conflict and loneliness.

The ‘burden’ of caring was being met by ‘informal carers’ from these communities and the research suggests that:

- Just as in the white community, carers in black communities are unsupported and isolated (McCalman, 1990; Katbamna *et al.*, 1997).
- Furthermore, just as in the white community, women are the mainstay of day care (Cameron *et al.*, 1988; Netto, 1996).
- The lack of support for and isolation of Black and Minority Ethnic carers is particularly exacerbated by communication difficulties (including carers of Chinese older people [Yu, 2000]), the lack of appropriate service provision, greater poverty, bad housing and racism (Gunaratum, 1990).

- The needs of Black and Minority Ethnic carers are numerous, ranging from education on health, diet and care to support with caring (McCalman, 1990).
- This appears to be combined with a continuing failure to recognise and respond to the needs of (Asian) carers, and this appears to be true of the experience in Scotland too (Netto, 1996; Katbamna *et al.*, 1997).

Conclusion

The studies reviewed here demonstrate that considerable health and social care needs exist amongst Black and Minority Ethnic older people. While the evidence on intensity is sketchy, it is clear that the inability to perform some basic tasks affects a comparatively younger group of Black and Minority Ethnic older people than white older people. This experience appears to be made worse by the dramatic evidence on the extent of poverty and poor housing. The comparative wealth of some Indian older people is in sharp contrast to the experience of the majority of Indian older people, in fact the majority of older people from minority ethnic communities. Finally, there is some evidence that 'family' or informal support is not available to some Black and Minority Ethnic older people who need it, while for others their 'carers' are not able to meet all their support needs. Again this situation appears to be made worse by a lack of adequate or appropriate services to meet the support needs of Black and Minority Ethnic older people.

4 Response of older people to findings

The three different groups generally felt that the findings of existing studies reflected their own experiences in their own areas.

There was agreement that the numbers of Black and Minority Ethnic older people in the general population were increasing and becoming more visibly an issue, but concern was expressed about how local services could respond to the needs of increasing numbers of older people. The point made was that there was a lack of help and support available on how services would meet the growing demand.

It was an uncomfortable fact but, directly or indirectly, mainstream services and mainstream society were still seen by the older people in the groups as being both ageist and racist. They said it was impossible to ignore this fact and it needed to be said.

From the experience of most of the older people there was an issue about having access to relevant information about services and there was agreement that more knowledge/information should be made available to Black and Minority Ethnic older people.

There was agreement that Black and Minority Ethnic elders are more likely than their white counterparts to face poverty and poor housing and examples were cited about people's individual experiences, which included no central heating, poor maintenance, lack of access to grants and the need for better housing.

They felt that organisations like the social services should be aware of changing family patterns and that the extended family may not be able to look after them. If they are living alone they needed to know what provisions will be available to them.

Other key themes

Mainstream or community services?

There was a great deal of frustration that, in the experiences of the Black and Minority Ethnic older people, the mainstream services did not meet the needs of different minority communities.

Language barriers in services

For some communities the problems were about the language barriers within services – in finding out what services were available or in getting those services to respond to the needs of different communities. Sometimes it was impossible for a

Somali older person (for example) to be sure that the health service understood the issues that they were raising (or that they understood what the doctor or nurse was recommending). There were often problems in explaining symptoms of ill health and busy GPs often did not give sufficient time (or have interpreters in place) to discuss with patients whose first language wasn't English. Often as a result of this conditions were misdiagnosed or diagnosis was very late. The Chinese community, for example, have found language barriers in health, social care and other services a real problem.

Often the problems were about information or advice – locally and nationally – on what to do or whom to approach. Sometimes this also meant asking that someone could help you to represent your views.

Culture, beliefs and values

The different groups said quite clearly that often the mainstream services do not meet the needs of culture, language and beliefs that are important to different minority communities. Sometimes this was about basics such as food, but at other times it was about a lack of knowledge and respect for religious beliefs and practices. Some Black and Minority Ethnic communities may have a different view of health and well-being, and find that their own views of complementary medicine or a holistic approach to health needs are not seen as being important or relevant. There were real frustrations here because often different communities felt that the Western mindset simply saw communities as 'problems' rather than respecting the fact that different communities had real strengths to be valued. Also older people felt that, in the present system, such preventive/alternative medicines were more costly than Western medicine and more costly than they would have been in the original countries.

Getting a service – lack of money

In many ways, the experiences of Black and Minority Ethnic communities in different areas had been that the main services seldom provided what minority communities wanted. It was more likely that community-based services would have fewer barriers and a better chance of meeting needs than mainstream services would. However there were disagreements in the meetings about what should be done next.

- Some had lost faith in major services and wanted services from and by their own community voluntary groups – sheltered housing, interpreters, advocacy, day centres, befriending services, counselling, financial advice and similar. These older people felt that the best routes to support (and their most positive experiences) had been when their own community voluntary organisations were adequately funded to undertake these tasks.

- However, others felt that the funding of community voluntary organisations let the mainstream services ‘off the hook’. They felt that the mainstream services should be addressing these issues and knew that, when budgets cuts were on the table, it was the community voluntary services who were the first to lose out.

Money matters

Some older people who had come to the UK during the 1950s and 1960s and had worked in public services said that they had not been properly advised on the need for pensions. Because of this, they had found themselves in later life in a poverty trap. Had better advice been available they may have been able to secure better provision in later years.

For some communities (some Asian groups and some Afro-Caribbean groups) poverty was the central issue. Many felt that it was ‘their lot’ to accept the poverty they had to face, but did not want their children or grandchildren to be in the same position. A review of income levels needed to be explored – particularly for those older people whose income was just above the threshold for benefits. In high-cost areas like London it was a problem to make ends meet.

Benefit entitlement was often poorly understood or not available in appropriate languages, or there was no one to explain what was available and how they might apply for it. It was recognised that this was a problem for older people more generally, but some Black and Minority Ethnic older people who had little contact with major services or whose first language was not English were more isolated from good information and advice here.

Health, well-being and relationships – community and family

Often there were inappropriate stereotypes about different communities ‘looking after their own’. In fact, the discussions in the different meetings highlighted that family members were more likely to live further away from each other than might be true in Britain as a whole.

There were also issues about changing values between generations. Of course, this was an issue more generally in society, but there could be a generational gap *and* a cultural gap between Black and Minority Ethnic older and younger people. This could leave older people feeling particularly isolated – often literally living alone.

It had been recognised in the research that older people from different minority ethnic communities were likely to experience the effects of ageing at a younger age. However, services showed little understanding of these issues.

There was a particular issue about mental health. Areas identified were dementia and depression. The isolation that Black and Minority Ethnic older people face led to high levels of depression and the need for more befriending services. Depression and mental health could be a taboo subject in some communities and there was a need to discuss these issues – but not in a way that left people feeling worried or exposed.

Issues of abuse were raised in the discussions. There were concerns that the idea of abuse (physical and emotional) should be looked into – this issue was mainly raised within the London group discussion and it is not certain how widespread this concern was.

In all of this, it was also important to recognise and celebrate the strengths that could exist in many minority ethnic communities. Often the networks of support were more valued than in society as a whole and often older people felt that they had important things to say about a good, balanced life worth living. Most of the time they felt that they were being seen as a problem to be solved rather than people with real strengths, knowledge and wisdom to share.

Shared views with older people generally

It was also important to recognise that older people from different communities (Indian, Pakistani, Chinese, Afro-Caribbean) had many of the same needs and faced similar issues to older people more generally.

- They faced similar issues about poor access and waiting times on trolleys in hospitals and for health care. A lack of follow-up from hospital to home was also seen as a problem.
- Preventive measures (about healthy eating, good exercise, a good day out!) were also important to retain and sustain a quality of life.
- There were shared problems about, for example, the cost of housing and of living in London or other areas where housing was expensive.
- Pensioner poverty was particularly acute among some minority communities, but pensioner poverty was a shared concern with many older people more generally.

- If housing was being designed for older people, that needed to include space for friends or relatives to stay. Older people needed a social and family life too!

The important message that came from the discussion was that there was not one specific formula that cut across all groups. Older people from different minority ethnic communities were different and often had specific needs and specific issues. And it was important to recognise that Black and Minority Ethnic older people often had much in common with older people from the majority community. In many respects the idea of a uniform ‘majority community’ of older people is, itself, misleading. Older people are different from each other too.

However it is also important to recognise the shared experiences of exclusion that Black and Minority Ethnic older people face – language, culture, ageist and racist assumptions – and to change mindsets as much as to develop specific services.

5 Discussion

The consultations with older people from Black and Minority Ethnic communities have raised a number of issues which are relevant both to the Foundation's Older People Programme and to the wider situation nationally.

The consultation groups were not trying to give an expert commentary on individual initiatives or specific pieces of research (though they often expressed the view that potentially good examples of practice seemed more likely to be found within community-based rather than mainstream services). Older people at the events had recognised that there were people and initiatives trying to make a difference. They felt that:

- Often (even possibly methodologically sound) research was, nevertheless, in their experience, poorly framed in terms of work that could make a difference to people's lives.
- Even good quality research did not necessarily, by itself, bring about change in policies or practice.
- There were many who had good intentions in practice. However, good intentions were not enough. It was important to think about how research or development initiatives might actually lead to sustainable good practice.
- In all of this, older people from Black and Minority Ethnic communities were (or should be seen as) central to defining good practice, its delivery and its reviewing.

In many ways, the results of this consultation are very similar to that coming out, more recently, from the Foundation's Race Equality and Disability Programme (Chamba *et al.*, 1999; Bignall and Butt, 2000; Yu, 2000; Bignall *et al.*, 2002; Evans and Banton, 2001; Hussain *et al.*, 2001; Netto, 2001; Visual Motions, 2001; Flynn, 2002; Jones *et al.*, 2002; Rai-Atkins *et al.*, 2002; Vernon, 2002).

In the JRF (internal) programme review of 2001 it was noted, however, that although research had uncovered a great deal about the exclusions that black disabled people and black older people faced, the issues persist. There is a challenge to move beyond a research agenda and to develop ideas in practice. There is also a need for older people from Black and Minority Ethnic communities to have a strong role in that shift. This will require funders, services and policy makers to develop their own approaches (in involving black older people; in sharing the setting of agendas; in supporting the development of exemplars of good practice) to achieve these ends.

Involving black older people

We have described in some detail the approaches before, during and after the 2001 consultations. These are not radical approaches, nor are they unique – nor have we always been able to live up to the ideals we have set ourselves.

There are many different possible designs for involvement, but there is a single strong message that came through. Black older people had frequently been consulted but seldom involved in the shaping of research or development work. The standards of involvement that the groups implied were about:

- being involved right from the start in initiatives
- having more than just one or two token members on a group
- having a real say in decisions about the initiative
- meeting regularly and having regular updates on progress
- being supported in the process and not simply left with a series of inaccessible papers to read
- being given the results of the research – not simply being the subjects whose knowledge is taken
- having a say in the meaning of the results and how these will be used.

These are not new messages – they are frequently mentioned by disabled people, older people and service users more generally. The challenge for all stakeholders – including funders – in this area is to respond.

The learning from within the JRF Older People Programme more generally has been:

- There is a need to experiment and change the balances of power.
- Be honest without sermonising.
- Use accessible approaches – formal meetings can empower officers and disempower people with the lived experiences of exclusion.

- Try to walk the talk. Involvement takes time and resources – even as evidenced in the meetings and timescales for this theme within the Older People Programme. It is important to be honest about this.
- You will make mistakes; you will underanticipate the needs of the group; you will overcommit with good intentions. The important point is to learn from this and develop better practice.

Within the JRF programme it has not always been easy (on all sides!) but we have tried to involve people from the start, frame the recommendations in terms of their priorities, feed back to them progress, develop projects which will make a difference, involve them in these projects and include them in discussions about where the projects are going and what they will achieve.

Some wider national issues

It is reassuring that the discussions among older people reflect so clearly the messages coming out of the research. However, as older people said at the consultation, we don't need more research to confirm what is already known. The next steps have to be about strengthening the hand of older people (individually and within their communities). At a national level, several possible areas of work follow on from the above discussion.

- Community voluntary organisations are the most likely to support older people from Black and Minority Ethnic communities (across all of the needs identified). Within the JRF Older People Programme and Race Equality and Disability Programme we are looking at what can be learned from the good examples of community organisations, teasing out the learning on how to support the development of community organisations and looking at ways in which older people can have more of a say in the community organisations which provide support.
- The mainstream services are still not seen as meeting their obligations to minority ethnic communities. How can mainstream services be supported (or encouraged) to change to be responsive to the needs of different minority ethnic communities? How can Black and Minority Ethnic older people (at a community level and at an individual level) get equal access to these majority services.
- Poverty among Black and Minority Ethnic older people is an important problem. What can be done to help in terms of affordable housing, access to pensions and benefits, adequate heating, good food and transport?

- The need for good housing, with appropriate support, is an important issue. However the different groups each expressed concerns about what the choices might be and how these might further isolate Black and Minority Ethnic older people from their own communities. The London group were probably the most critical about affordable housing.
- For some communities, the language barriers remain a central problem to be addressed. They were particularly excluded from accessing majority services and majority services did not hear (and often did not understand) Black and Minority Ethnic older people’s needs.
- It is important to recognise the issues of ageism and racism, but it is also important to have more positive representations of older people’s lives. Older people from Black and Minority Ethnic communities were frustrated with research which portrayed them as being a burden, rather than as having things to contribute. They had the experience of age and many experiences of life that were different to those of the majority of society. These should be acknowledged and valued. Older people would still need that bit of help, but they also wanted respect.

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