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The Consumers' View: Elderly People and Community Health Services

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CONTENTS

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Page

PART ONE:

PART TWO:

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ELDERLY PEOPLE AND COMMUNITY HEALTH SERVICES

PART ONE

What do elderly people and those who care for them want from community health services? Both general and professional managers in community health services and practitioners working with elderly clients will want answers to this question.

Conventional wisdom says that community health services – together with others provided by local authorities and voluntary organisations – should be geared to enabling elderly people to stay in their own homes for as long as possible. This, in fact, is where 97% of them live, and there is no shortage of articles and reports about new ways of trying to make this easier when they need help. But there is a great deal less material on what elderly people and their carers themselves want from services. So the first aim of this report is to draw together for managers and professionals information about how elderly people feel about what is available and how services might be improved.

It perhaps says something about the relative status of this group of health service consumers that such an exercise should still be necessary. Although there has been much talk of 'consumerism' in the health service during the past decade, and although 'consumer satisfaction' is likely to become increasingly important in evaluations of both services and those who manage them, older people tend to be seen as 'consumers' chiefly in discussions of how much they use health services, rather than of what they think of them. There is a feeling that they consume 'too much', that their rate of consumption represents a 'burden' on services which is getting worse as their numbers increase. It may seem harder to find out what elderly people think about services – and seem less important – because they tend to participate less in public life than other groups and to be poor.

But there is no justification for ignoring their views. Indeed, it could be argued that just because it is perhaps harder to discover them, working for 'consumer satisfaction' for this group could yield some important lessons on doing so more effectively for others as well.

The gains of such an approach are far from simply theoretical. A service that is designed to respond to the needs and wishes of its consumers will be more effective and less wasteful than one which is not. And it will plainly be easier to recruit, retain and motivate staff in a service which satisfies those who use it rather than leaving them dissatisfied and distressed. So this report should be useful to managers in community health services – and that includes heads of paramedical services used by elderly people as well as general managers – and to those who train all the many different workers who have contact with elderly people in their own homes.

The difficulties of developing effective community care are well known.[1] But as this report emphasises, most of the difficulties that elderly people and their carers experience have to do not with the organisational and financial obstacles that preoccupy planners and managers, but with relationships and attitudes. Negative perceptions of old age are part of British culture. Jokes, films and radio and television shows portray elderly people as either stupid, decrepit or feeble, or unusually eccentric, wise or sweetnatured and in any event to be patronised. To be old is to be in an ambiguous state, to be both honoured and feared.[2] To be old and black is to be doubly vulnerable to prejudicial attitudes.[3,4]

Health professionals are far from immune to these perceptions of old age. But they

1. Audit Commission for Local Authorities in England and Wales. *Making a reality of community care*. London: HMSO, 1986.

2. Hendricks J, Hendricks CD. Ageism and common stereotypes. In: Carver V, Liddiard P (eds). *An ageing population*. Sevenoaks: Hodder and Stoughton, 1978.

3. Standing Conference of Ethnic Minority Senior Citizens. *Ethnic minority senior citizens – the question of policy*. London: SCEMSC, 1986.

4. Norman A. *Triple jeopardy: growing old in a second homeland*. London: Centre for Policy on Ageing, 1985.

do have a special responsibility to be aware of their prejudices. Because this society credits professional and particularly medical judgements with a privileged access to the truth, they will have far-reaching effects. Most immediately, of course, they will affect the well-being of elderly people and their carers at times of particular vulnerability. On both counts, they – and the rest of us – have a right to expect that the health service and its workers will challenge negative prejudices about age, ageing and race.

One of the most constant complaints of elderly people and their carers – often elderly themselves – is that they are lumped together in a stereotyped and often apparently threatening mass – 'the old', 'the over 60s'. Yet age differences within the population aged 65 and over are at least as significant as those between children and teenagers, or people in their twenties and those in their forties.[5] The next chapter looks at some facts about the elderly population and those who care for them in an attempt to break down some of the blanket assumptions.

Despite important differences among those described as 'the elderly', however, some common conclusions can be drawn about what they seek from community health services. Chapter 2 sets the scene by looking at often differing perceptions of 'community care' by government, the public, carers and elderly people themselves. Chapter 3 examines how elderly people and their carers experience what is currently on offer under that heading from health services. Chapter 4 goes more deeply into the ageism and racism that too often taint these services. Part Two of the report gives guidelines for improving services and lists resources for action. Four main principles of high quality services are examined with the aim of finding ways of helping elderly people remain at home for as long as possible without putting undue strain on their relationships with carers. When we can show that community health services are accessible, responsive to individual needs, equitable and accountable we may be able to find 'consumer satisfaction' among their users.

[5] Cornwell J. Health beliefs in old age: the theoretical grounds for conceptualising older people as a group. In: Glendenning F (ed). *Working together for health: older people and their carers*. Stoke on Trent: Beth Johnson Foundation Publications, 1986.

WHO ARE THE CONSUMERS?

1

WHO ARE THE ELDERLY?

There are about 10 million people aged 65 and over in Britain, almost a fifth of the population. During the 1980s, this group in the population has increased, with the numbers of 'very old' people (over 85) growing more rapidly than the numbers of 'young old'.[1]

Out of every 20 people of pensionable age

- 14 are aged between 65 and 74
- 5 are aged between 75 and 84
- 1 is over 85

Differences of age, social class, gender and ethnicity are as important among them as they are in any other age group.[2, 3, 4]

People now in their late 70s and 80s were born at the beginning of this century. They lived through the First World War as young adults and came to maturity between the wars. Many of the men were too old to fight in the Second World War; many of the married women had completed their families by then and some went out to work for the first time. By contrast, people now in their sixties and early seventies were either children or not yet born in the First War, although they are likely to have taken part in the Second. Many people in this generation began their families shortly before the war or waited until after it; many women in war time were single parents. After the war, with the founding of the welfare state and the National Health Service, the lives of men and women in this generation became markedly different from those of previous generations.[5]

Health

There is some evidence that the very marked social inequalities in health found in younger age groups diminish in old age.[6] But there is relatively little evidence about social differences in morbidity and health among people over 65. Although we know that people over 85 use health services more that any other age group, generalisations about the health of older people need to be treated with caution.

Wealth

There are very marked differences in level of wealth, income and standard of living among older people. The elderly population contains people with great personal wealth and those who are very deprived – although the majority situation is of low incomes and poverty.[7]

Changes in income and wealth in the working population have had detrimental effects on the financial and social status of pensioners and others who do not work. Recent years have seen a consistent rise in the ownership of homes and of consumer goods such as fridges, televisions, videos, home computers, clothes and cars. Elderly people have not participated as fully in these changes as those in younger age groups. Their standard of living is not keeping pace with that of the working population and along with those in long-term unemployment and reliant on social benefits of different kinds, they are made to seem marginal to the rest of society.[3]

Gender

Women outnumber men at all ages over 65, because of sex differences inmortality. The ratio of women to men increases with age: among people aged 75–84 it is 2:1, while among those aged 85 and over it is 4:1.

[1] Office of Population Censuses and Surveys. Central Statistical Office. *Britain's elderly population: census guide 1: 1981 census.* London: HMSO, 1984.

[2] Office of Population Censuses and Surveys. *General Household Survey 1984.* Series GHS No 14. London: HMSO, 1986.

[3] Office of Population Censuses and Surveys. General Household Survey Preliminary Results for 1985. *OPCS Monitor.* GHS 86/1. London: HMSO, 1986.

[4] Evers H. The frail elderly woman: emergent questions in ageing and women's health. In: Lewin E, Olesen V (eds). *Women, health and healing: toward a new perspective.* London: Tavistock Publications, 1985.

[5] Cornwell J. Health beliefs in old age: the theoretical grounds for conceptualising older people as a group. In: Glendenning F (ed). *Working together for health: older people and their carers.* Stoke on Trent: Beth Johnson Foundation Publications, 1986.

[6] Townsend P, Davidson N (eds). *Inequalities in health: the Black report.* Harmondsworth: Penguin, 1982.

[7] Walker A. Pensions and the production of poverty in old age. In: Phillipson C, Walker A (eds). *Ageing and social policy: a critical assessment.* Aldershot: Gower, 1986.

Older women are less likely to have occupational pensions than older men, and more likely to be completely dependent on state benefits and pension for their income. They are also more likely to be widowed or single; more likely to live alone and more likely to end their lives in residential care.

Older women report more long-standing illness than older men, who report more acute, short-term illness. Women also say that their activity is more restricted by ill-health and appear to suffer more than men from loss of mobility.[6, 8]

It is not possible to tell from the evidence how much of what people say about their own health has to do with the cultural expectation that women and men *should* be different. It is possible that older women see themselves as more restricted and less mobile because they feel more vulnerable outdoors than older men, or because in old age and on the death of their husband they have to do things at home that used to be 'men's work'. Men may report less chronic illness because they prefer not to see themselves as physically vulnerable. Cultural differences between the sexes affect the way that younger women and men perceive their own health, and there is no reason to assume that these are less significant as people get older.[9]

Black and ethnic minority groups

The black and ethnic minority population in Britain is younger than the indigenous white population. In the 1981 census 33% of those living in private households where the head of household was born in the New Commonwealth and Pakistan (NCWP) were under 16 years old, compared with 22% of the white population. At the other end of the age scale, only 0.04% of such residents were aged 65 or over, compared with 17% of the white population.

These statistics apply to the country as a whole, but the picture can be different in areas where there are large numbers of people from black and ethnic minority groups. In the London Borough of Haringey, for example, almost a quarter of the population aged between 60 and 64 (24.5%) and almost a fifth of the population aged between 65 and 74 (19.3%) belong to black and ethnic minority groups.[10]

Knowledge is very limited about health needs of older black and ethnic minority people and about how, if at all, these differ from those of the indigenous white population. The phrase 'ethnic minority' says relatively little about the people it purports to describe. In Haringey, for instance, the 'ethnic minority' population includes people born in Eire, in the Mediterranean, in the New Commonwealth and in the Caribbean; and a very large group is simply described as coming from 'the rest of the world'.

People of different ethnic origins who have settled in Britain will clearly bring a huge variety of life experiences to their old age. The experiences of the Jewish and other refugees who came to this country before the second war, and of the Poles who remained here after it, will be very different to those of the Afro-Caribbeans who came in the 1950s and 1960s, often to work in public services and often in the now-fading hope of retiring to their original homeland. Elderly Asians who came to join their children here will have had very different life experiences from the single Irishmen who came in the 1920s and 1930s and have often spent a working lifetime as itinerant labourers. Each of these groups and the many others may experience particular difficulties as they get older.[11] Nevertheless, they may also share a common expectation of old age, which may be very different from its actuality in Britain today. "Whether these people came from the Indian sub-continent, the Caribbean, Africa, Cyprus, Hong Kong or wherever, their experience of ageing would have been similar", says the Standing Conference of Ethnic Minority Senior Citizens.

> "In old age they would have been accorded due respect and status: they would not have known about age segregation: they would have assumed an important role, not only within the family structure, but within the community. At no point along the ageing continuum would they have been dismissed as useless or roleless. In the world they conceptualise, old age or retirement is not synonymous with abandonment. For many of them retirement would have been viewed very differently, the official role giving way to an equally, sometimes more, fulfilling unofficial role. Many others, particularly those from the rural areas, would have no concept of retirement – the work ethos maintaining its hold to the very end of life."[12]

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8. Taylor R, Ford G. Inequalities in old age. *Ageing and Society*, 1983; 3, 2: 183–208.

9. Wenger C. What do dependency measures measure? Challenging assumptions. In: Phillipson C, Bernard M, Strang P (eds). *Dependency and interdependency in old age – theoretical perspectives and policy alternatives*. London: Croom Helm, 1986.

10. Department of Community Medicine. *Black and ethnic minority elderly*. London: Haringey Health Authority, 1986.

11. Norman A. *Triple jeopardy: growing old in a second homeland*. London: Centre for Policy on Ageing, 1985.

12. Standing Conference of Ethnic Minority Senior Citizens. *Ethnic minority senior citizens – the question of policy*. London: SCEMSC, 1986.

Recent studies of elderly people from black and ethnic minority groups – particularly Afro-Caribbeans and Asians – have confirmed some other common themes. These elderly people are generally poorer than average, Asians in particular lacking any pensions or benefits. They bring to their retirement a history of low earnings in mostly unskilled work, with high unemployment – and the health problems that may be associated with these. They live in poor and often overcrowded housing, in inner cities or unpopular estates. And they experience continuing harassment.[13]

The association between culture, race, social conditions and mental illness is complex and controversial.[14] But it has been suggested that the loss of homeland and status, together with communication difficulties that may be exacerbated when English learned as a second language is forgotten, make elderly people from black and ethnic minority groups particularly at risk of mental distress.[11]

There is evidence that being a migrant and being black adds considerably to the stress of ageing, and that there may be important differences within black and ethnic minority populations in the use that old people make of the health services generally. The popular idea that all black and ethnic minority peoples care for their older relatives is neither supported nor refuted by the evidence. If true, it is probably so for only a small proportion of elderly people in specific groups.[15, 16]

WHO ARE THE CARERS?

At least 1.7 million people care for disabled and elderly relatives at home. If people who care for someone in a different household are included, the total rises to about six million carers in Great Britain. One household in five contains a carer. Half of these carers are looking after someone over the age of 75. Fifteen per cent are caring for someone over the age of 85.[17]

The majority of carers is already middle-aged, and a sizeable minority is old. Of those caring for more than 20 hours a week, 26% are over 65. Some areas have high proportions of older carers. Surveys in Essex and Nottingham have shown that up to a fifth of carers (14–20%) are over 75.[18]

Most carers are related to the person they look after. Only a quarter of those caring for someone in another household are looking after friends. In the same house, 40% are caring for their husband or wife and 29% for a parent or parent-in-law. Ten per cent are older carers looking after their own children of 16 years or more.[17]

Because many carers are themselves elderly, and because their work is often stressful and damaging to physical and mental health, they too are consumers of health services. Nationally, half the carers over 45 report a long-standing illness. In the Essex survey, 61% of carers had specific health problems. Nearly a third (31%) suffered from physical illnesses, such as arthritis and heart conditions, that made it more difficult for them to care. Nearly a quarter (23%) showed signs of physical strain, like hernia and back trouble. A further fifth showed other signs of strain, including depression, insomnia, migraine and problems with blood pressure.[18]

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13. Glendenning F, Pearson M. *The black and ethnic minority elders in Britain: health needs and access to services*. London: Health Education Authority in association with the Centre for Social Gerontology, University of Keele, 1988.

14. Littlewood R, Lipsedge M. *Aliens and alienists*. Harmondsworth: Penguin, 1982.

15. Blakemore K. Health and illness among the elderly of minority ethnic groups living in Birmingham: some new findings. *Health Trends*, 1982; 14: 69–72.

16. Blakemore K. Ethnicity, self-reported illness and use of medical services by the elderly. *Postgraduate Medical Journal*, 1983; 59: 45–47.

17. Green H. *Informal carers. General Household Survey*, 1985. Series GHS no 15 Supplement A. London: HMSO, 1988.

18. Cooper M. *Hard-won reality: an evaluation of the Essex Crossroads Care Attendant Scheme*. Colchester: Essex County Council Social Services Department, 1985.

2

COMMUNITY CARE: WHOSE PREFERENCE?

Community care has been an official policy for old people since the 1950s. But it means different things in different contexts and to different people. There seems to be a consensus that old people should be able to remain at home 'for as long as possible', but opinions vary about what this actually means and who should do the caring. This chapter explores current attitudes to the care of old people in the community.

OFFICIAL PREFERENCES

The government's 1981 white paper *Growing Older* is clear: the "primary sources of support and care for elderly people are informal and voluntary" and the role of public services is to provide "a framework of support" consisting of technical and specialised assistance to old people and informal carers. Informal and voluntary care, says the white paper, is superior to the care of public services because it springs from the irreplaceable "personal ties of kinship, friendship and neighbourhood". Families are "as they always have been, the principal source of support and care . . . best placed to understand and meet the wide variety of personal needs which arise". Where elderly people have no family, responsibility for their care should rest with the "wider community".

> "Informal help of this kind is widely available. Regular callers such as milkmen and postmen keep an eye on elderly people, especially those living alone, and in many areas Community Service Volunteers, Task Force helpers and voluntary street wardens visit elderly housebound people and do routine jobs for them."[1]

What do the rest of us feel about this?

PUBLIC PREFERENCES

Most people seem unconcerned about community care until they themselves feel immediately implicated, usually when they or a member of their family needs to be cared for at home, or when there are plans to build a community home or hostel nearby. Information about public views on how old and other dependent people should be cared for is extremely limited.[2] But there is evidence to show that most women – who make up the vast majority of informal carers – want care *in* the community, primarily by public health and social services, rather than care by the community of relatives, friends and neighbours.[3] The one large survey of public preferences for the care of people in all the 'priority care' groups – children, old people, people with mental illness, learning difficulties and physical disabilities – supports this view. "The public as a whole are strongly supportive of professional and service involvement in the care of a dependent person."[3]

This survey shows that people's preferences differ according to who the dependent person is and whether they themselves feel implicated in the work of caring. Opinion differentiates sharply between old people with physical disabilities and those with mental ones. The public wants people in the first group to be cared for at home, with extensive support from public services; purpose-built flats with a warden on call seem the ideal solution for old people unable to look after themselves. A small minority thinks it appropriate to rely on informal and family care alone; an even smaller one that the old person should live with an adult child. The majority preference for old people with a mental disability, by contrast, is that they should be removed from the community altogether and looked after in geriatric hospitals or in old people's homes. This is the only example of public endorsement of the notion that any of the 'priority care' groups is better placed outside the community in institutional care.

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[1] Department of Health and Social Security. *Growing Older*. London: HMSO, 1981. Cmnd 8173.

[2] Glennerster H with Korman H, Marslen-Wilson F. *Planning for priority groups*. London: Martin Robertson, 1983.

[3] West P, Illsley R, Kelman H. Public preferences for the care of dependency groups. *Social Science and Medicine*, 1984; 18, 4: 287–295.

Public preferences do not vary according to the age, social class or religious affiliation of the respondent. But women, who make up the majority of carers, are markedly less supportive than men of informal and family care for any of the 'priority care' groups, and more supportive of public services.

CARERS' PREFERENCES

There is even less published material about the preferences of carers than about the preferences of the general public. But small qualitative studies show that carers, including those from ethnic minorities, have generally felt that they had no option.[4,5,6] Very few have made a conscious or deliberate choice to become carers, or indeed fully understood what they were undertaking. Most often they simply 'became involved' either through a long series of barely perceptible changes in a once interdependent relationship, or through having to respond to a crisis. The motivation for becoming a carer is rooted in a sense of obligation, family responsibility and 'duty' as much as in feelings of love and affection, and it can be hard for carers to talk about the various assumptions and factors that lie behind their decision. Geographical proximity and the lack of paid work figured prominently among their reasons for taking on the caring job, as did concepts of the family and of women's responsibilities. There was also the idea that some people were inherently suited to the role: "some people just automatically look after other people. In families some get stuck with it."[5]

The evidence suggests, then, that most carers do not have the freedom to choose whether or not to care.[4, 5, 6, 7] They simply become carers in situations where thoughts, feelings and motivations are extremely complex. Most know little about domiciliary services, which adds to the difficulty of seeing what they do as a real choice. We do not yet have enough information to be able to say whether being a carer represents a choice which is relevant to public policy, or simply a forced response to situations that are currently without practical alternatives.

OLD PEOPLE'S PREFERENCES

The vast majority of old people, it seems, agree with the principle of domiciliary care if it means helping people to stay at home. Of a sample of people aged 75 and over, no fewer than 98% agreed that it is desirable to stay in one's own home for as long as possible. They felt this for reasons of 'independence' and feeling happier at home amongst one's own belongings. They talked of the dangers of being 'uprooted'.[8]

But old people's attitudes to being cared for by relatives or friends are ambivalent. They seem to expect help at home and to think it reasonable that relatives should make sacrifices. But they also say they do not think daughters should have to give up work to look after an ageing parent, that help is not as freely given as it used to be and that caring for an ageing relative can cause family problems.[8] There is evidence of a powerful feeling amongst old people of not wanting to be 'a burden' and of a fearful appreciation of how destructive 'being a burden' can be to close relationships.[4, 5] Again, the level of awareness of domiciliary services amongst old people is so low that it is hard to know how far the preference for staying at home and being cared for by relatives and/or friends is an informed choice or a response to a situation in which there seems to be no alternative.

Most old people do, however, have a lively awareness of institutional care. The least popular form is the specifically geriatric facility, closely followed by residential homes and Part III accommodation. Old people – like many others – see geriatric wards and hospitals as places where patients are neglected and poorly treated, and they object to old people's homes on the grounds that they deprive their inmates of independence and autonomy. Some old people, though, feel that there are circumstances – principally being bedfast or incontinent – in which they would consider institutional care as a positive option. These tend to be people who live alone and do not have anyone in their informal network who could care for them.[8]

There are disproportionately few elderly people from black and ethnic minority groups in residential care or sheltered housing – even in cities like Liverpool where there has been a sizeable black population for many generations.[9] The idea of living in a setting which is quite unadapted to their culture and customs may be particularly

4. Finch H. *Health and older people: attitudes towards health in older age and caring for older people*. London: Social and Community Planning Research. 1985.

5. Bell R. Gibbons S. Pinchen I. *Patterns and processes in carers' lives: action research with informal carers of elderly people*. London: Health Education Council. 1987.

6. Anonymous. Ethnic minority carers – the invisible carers. *Health and Race*. 1988; April/May.

7. Equal Opportunities Commission. *Caring for the elderly and handicapped: community care policies and women's lives*. Manchester: Equal Opportunities Commission. 1982.

8. Salvage A. *Attitudes of the over 75s to health and social services*. Cardiff: Research Team for the Care of the Elderly. University of Wales College of Medicine. 1986.

9. Barker J. *Black and Asian old people in Britain*. Mitcham: Age Concern England. 1984.

distressing to these elderly people.[9, 10] They may feel particularly strongly that it is families who should be responsible for care.[11] But as the numbers of black and ethnic minority elderly people grow and more and more live either alone or with one other person, or experience loneliness and isolation even when living with their family, the 'last resort' of residential care may increasingly be considered – often with the hope that some new form of it will be offered that is 'more like home'.[12]

At the moment, we know very little about what people feel about the policy of caring for older people in the community. But we know enough to recognise the potential for conflict between different groups about how the policy is interpreted. The official view that people should be cared for primarily by their relatives, friends and neighbours is apparently favoured by old people themselves. But the public at large, and particularly women, would prefer community care to be primarily by public services. All the studies, though, make it clear that people do not know enough about the realities of services to elderly people in the community to be able to give an informed view of public policy.

10. Standing Conference of Ethnic Minority Senior Citizens. *Ethnic minority senior citizens – the questions of policy*. London: SCEMSC, 1986.

11. Bhalla A, Blakemore K. *Elders of the ethnic minority groups*. Birmingham: All Faiths for One Race, 1981.

12. Fenton CS. *Race, health and welfare*. Bristol: Department of Sociology, Bristol University, 1984.

COMMUNITY CARE: THE CONSUMERS' EXPERIENCE

3

Relatively little is known about how elderly people and carers would like community health services to develop. But there is some information about what they find problematic in services currently available. They voice very positive feelings about existing services, too, and about the staff with whom they come into contact. But this report seeks to find out how community health services can be made more responsive to their needs. So an obvious starting point is with aspects of services which are known to cause problems.

The discussion of consumers' views in this chapter is organised under four headings: information; coordination and flexibility; matching needs and services; and staff attitudes.

INFORMATION

Consumer surveys, whatever the age of the respondents, report that the public wants more information from professionals about health services.[1] Elderly people, however, seem to feel the need more intensely than most, perhaps because they are comparatively poorly informed. Carers too want more information: one of the things that makes life especially difficult, they say, is not knowing what they are entitled to or where to go for help.[2]

Very large numbers of elderly people who need help at home do not understand the role of different professionals, or even that there are services to help them. When they are aware of what help is available, they are uncertain how to obtain it. In one study, 40% of those aged between 65 and 74 and half of those aged over 75 who had not had recent contact with a district nurse did not know what these workers did. Even fewer people understood the role of health visitors or knew that they sometimes visited old people at home – 77% in the younger age group and 83% of those over 75.[3]

Relatives and friends are a major source of information about services for elderly people. These people, however, do not form a distinct and identifiable group, so it is hard to target information towards them. If information is to reach them, there needs to be a general increase in the level of awareness about services, and this would require a massive publicity effort.[4]

Elderly people therefore rely heavily on health and social service professionals for information. General practitioners are the most important resource, as they see over 90% of their patients aged 70 and more at least once a year.[5] After them come community nurses and home helps.[6] But health professionals themselves need to be better informed about the full range of community services if they are to be a useful channel of information for elderly people. Many too need to be convinced not just that it is part of their job to tell people about services, but that old people are capable of absorbing new information. The only health professionals who definitely see providing information about services as part of their job are health visitors and geriatric visitors. But health visitors are spending less time with old people and only a small minority of health authorities employ geriatric visitors.[7] District nurses spend a great deal of time with old people compared with other community nurses, but they may not see the need to use the educational or counselling parts of their role with them.[8]

There is no scientific evidence that age itself impairs learning abilities and a considerable amount to suggest that people of any age can take in information that interests them. Pensioners' health groups and organisations often say they would like health professionals to teach them both about services and about how they can look

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1. Leneman L, Jones L, Maclean V. *Consumer feedback for the NHS: a literature review*. Edinburgh: Department of Community Medicine, University of Edinburgh, 1986.

2. Bell R, Gibbons S, Pinchen I. *Patterns and processes in carers' lives. Action research with informal carers of elderly people*. London: Health Education Council, 1987.

3. Itzin C. *Elderly people in the community: screening, support and services*. London: Newham Health Authority, 1986.

4. Epstein J. *Information needs of the elderly*. Research Institute for Consumer Affairs, 1980.

5. Ritchie J. *Access to primary health care*. An enquiry carried out on behalf of the UK health department. London: HMSO, 1981.

6. Salvage A. *Attitudes of the over 75s to health and social services*. Cardiff: Research Team for the Care of the Elderly, University of Wales College of Medicine, 1986.

7. Phillipson C. Health visiting and older people: a review of current trends. *Health Visitor*, 1985; **58**, 12: 357–358.

8. Dunnell KL, Dobbs J. *Nurses working in the community*. London: HMSO, 1982.

after themselves, but their requests are only slowly beginning to be taken up.[9, 10] Health professionals have on the whole left it to community groups and voluntary organisations to satisfy the health education needs of elderly people and carers.

Lack of information about services is particularly widespread among elderly people from black and ethnic minority groups, especially the various Asian communities. Printed material tends to be about specific health topics, such as rickets or TB, rather than about services, and is in any case inaccessible to people who may go seldom into the community and cannot read any language.[11] Carers too suffer because they do not know about the range of health and social services, which leaves them feeling not just frustrated but isolated and uncared for.[12, 13] Bilingual women who act as go-between for elderly people, their carers and services have a particularly valuable role. But the stress on them is considerable, and they suffer from lack of recognition.[12]

Evidence has been growing during the 1980s of the extent of lack of knowledge about services among elderly people from black and ethnic minority groups and their carers. In one Birmingham study, nearly two thirds of elderly Asian respondents had heard of none of the seven community services listed, compared with 3% of Afro-Caribbeans and 2% of Europeans.[14] Even where elderly people might seem to have a particular use for services, knowledge about them could be scant. In a study of elderly people who were frail or mentally infirm and others who were physically disabled, over half the black respondents didn't know about the district nursing service and nearly three quarters didn't know about nursing auxiliaries; among the white respondents, the proportions were 14% and a third respectively.[15]

The one community health service with which elderly black people seem to be in good contact is that provided by the GP; there is some evidence that they visit the surgery rather more often than elderly white people.[14, 16] Yet even where a GP speaks the relevant language he may not see giving information about the range of available services as part of his job. One elderly Gujarati-speaking woman, very restricted by ill health, said that her Gujarati-speaking GP was 'like her son'. But she and her husband did not know about the financial benefits for which they were eligible, or about relevant aids for the kitchen and bathroom, or about the district nursing and chiropody services.[17]

[9] Hanson-Kahn C. Challenging the myths. *Voluntary Voice*. 1987; 12 Feb: 11.

[10] Meade K. *Challenging the myths: a review of pensioners' health courses and talks*. Agewell Campaign and Pensioners' Link, 1986.

[11] Ealing Community Health Council. *Provision of health services to the immigrant elderly in Ealing*. London: Ealing Community Health Council, 1983.

[12] Anonymous. Ethnic minority carers – the invisible carers. *Health and Race*, 1988; April/May.

[13] Bulsara S. Services – for all? *Carelink*, 1988: **6**, winter: 2.

[14] Bhalla A, Blakemore K. *Elders of the ethnic minority groups*. Birmingham: All Faiths for One Race, 1981.

[15] Badger F. *et al*. Put race on the agenda. *Health Service Journal*, 1988: **98**: 1426–1427.

[16] Fenton CS. *Race, health and welfare*. Bristol: Department of Sociology, Bristol University, 1984.

[17] Moledina S. *Great expectations: a review of services for Asian elders in Brent*. London: Age Concern Brent, 1987.

COORDINATION AND FLEXIBILITY

Elderly people very often use more than one service at a time. A disabled old person who lives alone and has a fall, for instance, may be admitted first to hospital and then into residential care. This one person could have had contact with most, if not all, of the following: GP; home help/home care assistant; meals on wheels; district nurse; night sitter/bath attendant (voluntary or statutory organisation); specialist community nurse; chiropodist; physiotherapist; occupational therapist; geriatric visitor/ liaison nurse; medical social worker; hospital medical and nursing staff; hospital therapist; residential care staff.

The involvement of so many agencies and organisations in the provision of community services means that the professional relationship between individual consumer and professional is at a premium. Without this, old people and their carers can very quickly begin to feel that although their problems are being 'dealt with' – dressings changed, shopping done, bathing and toileting completed – they are not truly cared for.

To the professionals, the system may make sense. But old people and carers would like to be told who everyone is and what they can expect of them. They would also like to be consulted about visits to their homes and would prefer that the arrangements of one professional do not conflict with those of another. Lonely people who are regularly visited by a number of different organisations would prefer the visits to be spread over the week rather than, as sometimes happens, all falling on the same day.[2]

Professional help that comes at the right time and, most importantly, recognises and supports their own contribution, can be of very great value to informal carers.[18] But for many, and especially those looking after the mentally frail, the support they get often feels peripheral to their own 24-hour responsibility and commitment. The

[18] Bell R, Weir F, Pinchen I. *Action research with informal carers of elderly people*. London: Health Education Council and Health Promotion Service Cambridge, 1987.

most important thing for carers may be that professionals are available at the times they need them. If they are not, they may actually make life harder. One carer reported, for instance, that she had lost help bathing her husband when his one visit to the day centre was changed to the only day that the district nurse came to the village. Another was doing her mother's housework because the ambulance which took her mother to the day centre arrived so early that there was no one to let the home help in. Help must arrive at a time that is predictable and convenient to the carer if it is to achieve what it sets out to do.[2]

MATCHING NEEDS AND SERVICES

Tudor Hart's 'inverse law of care' states a reality: patients with the greatest need get less from the NHS in terms of both quality and quantity than those whose needs are less.[19] Elderly people suffer two types of mismatch in community health services: occasionally, services do too much; more often, they do too little. Lack of communication between different parts of the service can lead to 'over-provision', and inappropriate or over-zealous intervention can undermine the patient's sense of independence.[20, 21] Underprovision particularly affects severely physically and mentally disabled old people and their carers. These frail and dependent old people on the whole live either in institutions or with someone who looks after them. Their carers have an intense need for support and relief, but they actually get *less* help than carers who live separately from less severely disabled old people.[22, 23]

Carers of mentally disabled old people are under the most severe stress of all, yet they get less outside help even than other resident carers, because of the difficulty of finding someone who is prepared to relieve them. They receive less help with washing, bathing and lifting and also have fewer breaks, even for as little as an hour or two a week. Mentally ill old people are less likely than others to attend day centres and day hospitals, so their carers do not get regular relief. A recent survey of about 250 carers showed that fewer than half had managed to get away even for a few days during the year, and that those who had managed it were more likely to be non-resident carers. Only 30% of the carers of mentally ill old people in the same survey had an annual holiday at all, and 4% of those looking after people with severe memory impairment had not had a holiday of one week or more in five years.[23]

Underuse of community services by black and ethnic minority elderly people is well documented. Yet there is no evidence that their needs are less than those of the white majority. There is, however, some evidence of mismatch between need and services among elderly people from black and ethnic minority groups.[24]

One Birmingham survey into the needs of physically disabled and frail and mentally infirm elderly people at home shows that 7% of clients of community services in these categories were black. But only 3.5% of the clients of district nurses were black – even though they generally count elderly and disabled people as a major client group. Yet when non-users of the district nurse and nursing auxiliary services were asked if they would consider using them, a similar proportion of black and white respondents said they would.[15]

Elderly people from black and ethnic minority groups may have more untreated ailments than elderly white people. One Birmingham study found that although elderly Afro-Caribbean people went more often to their GP, they had more untreated problems of eyes, feet, ears and teeth.[14] A study of elderly black people in Leicester found that although just over a quarter said they were 'very depressed' and a third 'forgetful', only 4% of those who said they were depressed were receiving any treatment. (This was a particularly vulnerable sample: 28% lived alone, 56% felt it was unsafe to go out alone at night and 30% had problems of physical mobility.)[25]

STAFF ATTITUDES

The attitudes of health professionals are very important to patients, as the frequent comments of patients' and consumers' organisations show. Old people and their carers feel especially strongly about professionals' attitudes, and about the need to be treated as individuals, and with as much respect as would be accorded to younger patients. They are also often anxious about people being grouped together, especially in facilities or wards for 'geriatric patients'.[6, 26, 27]

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19. Tudor Hart J. The inverse care law. *Lancet*. 1971; **i**: 405–412.

20. Brody EM. Environmental factors in dependency. In: Exton-Smith AN, Grimley Evans J. *Care of the elderly: meeting the challenge of dependency*. London: Academic Press, 1977.

21. Evers H. Old women's self-perceptions of dependency and some implications for service provision. *Journal of Epidemiology and Community Health*. 1985; **38**: 306–309.

22. Jones D, Vetter N. A survey of those who care for the elderly at home: their problems and their needs. *Social Science and Medicine*. 1985; **19**, 5: 511–514.

23. Jones D, Vetter N. Formal and informal support received by carers of elderly dependents. *British Medical Journal*. 1985; **291**: 643–645.

24. Glendenning F, Pearson M. *The black and ethnic minority elders in Britain: health needs and access to services*. London: Health Education Authority in association with the Centre for Social Gerontology, 1988.

25. Farrah M. *Black elders in Leicester*. Leicester: Leicestershire County Council, 1986.

26. Brent Community Health Council. *Health care in Brent: a workers' and users' enquiry*. London: Brent Community Health Council, 1986.

27. Scrutton S. I don't like to complain, dear. *Community Care*. 1986; 4 Dec: 20–21.

Old people know they are the objects of pity to some and of disgust or fun for others. They know that health professionals sometimes refer to them as 'girls and boys', 'geriatrics', 'wrinklies', 'crumble', 'crocks'. To be labelled senile, stupid, feeble or incompetent simply because of age is barely tolerable at any time. It is unbearable when it comes from the health professionals on whom the old people – and carers too – feel so dependent.

Old people want their health problems to be taken seriously. But too often, they complain, they are fobbed off by health professionals with the notion that it is age alone that is responsible for their ills.[9] One of the more popular cartoons in pensioners' publications is the one which depicts a doctor bent over an elderly woman's leg and saying: "It's your age!" Her reply is: "But the other one is just as old, and it's alright!"

Elderly people from black and ethnic minority groups may experience particular difficulties because of professionals' attitudes. Mutual language difficulties can clearly exacerbate these: the use of relatives as interpreters, particularly if they are children, is generally seen as unsatisfactory; so is the widespread practice of calling on staff who may speak the needed language but are neither trained in the delicate skill of interpreting nor employed as interpreters.[11]

Elderly Asians in particular often speak of the need for greater sensitivity from health service personnel. While the brusqueness and impatience reported of doctors and receptionists would be recognisably part of the experience of many elderly white people, these attitudes may have an added edge for people who have experienced racism in other areas of public and social life. Attitudes of health service staff may, for some, confirm that they are 'second class citizens'.[16]

Sometimes, staff attitudes may seem little short of threatening. Elderly Asian people in one London study reported that they simply didn't know what was going on when district nurses visited (without an interpreter) and gave them treatment. In another part of London, an elderly Asian woman reported: "When the district nurse calls, I just freeze. I don't know what she is expecting from me. I don't know what to do. When she bathes me, I don't move a muscle unless she does, in case I upset or anger her."[17]

Consumers of all ages say they would like more information about and easier access to health services. They increasingly want professional staff to discuss their health problems with them and to consult them over decisions about their treatment and care. The concerns of elderly people and their carers are no different and the problems they experience are not unique. Nor are the reasons for their difficulties. For them, as for other groups, these very often have to do with conflicts over priorities and service objectives, battles for resources between acute and community health services and the nature of medical status and rewards and professional training.

There does, however, seem to be something exceptional in the degree to which old people and their carers experience difficulties and feel the need for improvements. The next chapter tries to explain some of the reasons for this by examining in more detail professional attitudes towards old people and the meanings associated with age.

QUESTIONS OF ATTITUDE

4

AGEISM

Ageism, or negative discrimination on grounds of age, can affect any age group, but in contemporary Britain it is most commonly practised against old people. It is this that marks out the health care they receive as different from that offered to younger patients.

Public services are ageist when they single out old people from other age groups and treat them in a different and detrimental way. Professionals are ageist when they categorise people simply in terms of their age and apply age-based stereotypes to them. Ageism in the health service is expressed structurally as well as in styles of professional practice. In theory, old people are a national 'priority care' group. But it has proved difficult to shift resources out of the acute sector and into the priority and community health services.[1] Furthermore, work with old people in both health and social services is generally considered low status; it is poorly rewarded and tends to be done by the least qualified staff.[2]

There have been some changes in the past decade, notably in the speciality of geriatric medicine, which has grown numerically and increased in status within the medical profession.[3] But the care of old people in the community is still mainly carried out by the least qualified staff. Training is limited, and directed more towards 'geriatric care' and rehabilitation than towards a 'gerontological' perspective which might promote positive approaches to ageing people. Health visitors, the only group of community nurses with a specific brief for prevention and health promotion, have very little to do with old people, while district nurses, the bulk of those whose work is with this group, have shown little interest in departing from a geriatric model of care to develop a more positive approach towards ageing. Although many health visitors say that they are interested in working with old people, they do not, perhaps because they know neither how to structure their visits nor whether to adopt a developmental or a curative model of practice.[4]

The professional paradigm – the set of concepts, theories, beliefs and ideas that constructs the way that health professionals perceive old people and conceptualise their needs for services – is ageist, both because it is negative and because it provides a basis for discrimination. Within this paradigm, old people are seen as 'a burden on the welfare state'; dependent; and deeply conservative and fatalistic.

'A burden on the welfare state'

The idea that old people are a burden on the welfare state derives from an emphasis on their increasing proportion in the population and from technical discussions in the literature of economics and social administration about 'dependency ratios'. Both simultaneously reinforce and are reinforced by the common association between old age and mental and/or physical frailty.

Most of the texts relating to the provision of services to old people start with statements about their increasing numbers. This example is typical:

> "Changes in the structure of the population have been a cause for increasing concern among social scientists and planners . . . The trend for elderly people to live longer and continue living independently has been widely reported, and even though the rapid rise in numbers of the elderly is projected to level off, a fall in the numbers of the 65–74 cohort is likely to be balanced by a future increase in the 75-plus age group. It is the least dependent group (those aged 65–74) whose proportion is decreasing, whilst the proportion of those aged 75 and over is increasing. Between 1901 and 1981, the numbers of those aged 75 and over increased by 621%, from

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[1] Glennerster H with Korman N. Marslen-Wilson F. *Planning for priority groups*. London: Martin Robertson. 1983.

[2] Norman A. *Aspects of Ageism: a discussion paper*. CPA Paper No. 2. London: Centre for Policy on Ageing. 1987.

[3] NHS Health Advisory Service. *Annual Report (June 1984–June 1985)*. Sutton: NHS Health Advisory Service. 1986.

[4] Phillipson C. *Health education and old people: developing positive approaches in district nursing and health visiting*. Evidence to the Community Nursing Review. Keele: Department of Adult Education. University of Keele. 1985.

> 396,000 in 1901 to 2,856,000 in 1981, and their numbers will increase to an estimated 3,314,000 in 2001 . . .”[5]

Planners need to pay attention to demographic changes and to get the guidelines right.[6] But the tone of passages like these is alarmist and the imagery used is often strikingly negative. Old people are presented as a ‘rising tide’ of the very needy, very dependent, which, by implication, is threatening to overwhelm ‘us’ and to swamp ‘our’ services. The same imagery would hardly be applied to a large projected rise in the number of children. There is no knowing how far perceptions of old people’s entitlement to care have been affected by this kind of language, but it would be surprising if it had not had some negative effect.

5. Salvage AV. *Developments in domiciliary care for the elderly*. King’s Fund Project Paper No. 48. London: King’s Fund Centre, 1984.

6. Grundy E. Community care for the elderly 1976–84. *British Medical Journal*, 1987; **294**: 626–629.

Dependence

Old age appears to be inextricably linked in the minds of both public and health professionals with dependency.[7] Popular images are partly the products of people’s fears and projections about what will happen to them – in this case, of younger people’s fears and projections about growing old. But the images are also partly constructed from storybooks and the media, where we are used to seeing old people as victims, as poor, isolated, ugly, physically disabled, senile, frail and incontinent.

There is no reason why health professionals should be immune from this popular imagery, and challenging stereotypes is rarely included in their training. However, it is assumed that their concepts of ‘dependency’ are somehow more scientific and objective than those produced by commonsense. Yet the most commonly used measures of dependency in the literature rely on individuals’ own assessments of the degree to which illness or disability restricts their ability to perform everyday tasks. These so-called objective measures of subjective assessments take no account of the many factors that affect people’s notions of what they are or are not capable of doing. Culturally-determined expectations of what a person of a particular age and sex should be able to do, for instance, or the variation in individual self-perceptions that springs from different personalities and life experiences, may both be influential.[8, 9]

Psychological differences between individuals may affect whether or not they say they need help with everyday tasks. Some people are always eager to present themselves as independent; others confess very readily to needing help. Some elderly people are ‘active initiators’: they are objectively dependent on others, but feel themselves to be in control and responsible, and so, in a very important sense, independent. Others are ‘passive responders’: they need comparatively little help from others, but feel themselves unable to function without outside help. The standard scientific measures of dependency used by professionals are not capable of distinguishing between objective and subjective needs for care, however. So intervention may be inappropriate to individual need. Over-zealous intervention can undermine the active initiator’s sense of responsibility and control; insufficient outside help can defeat whatever small effort the passive responder may be able to make on their own behalf.

What the standard measures do offer, however, is a professional stamp of approval for the popular idea of old people as necessarily dependent. This makes it more difficult for health professionals to treat each old person as an individual with their own particular relationship to and need for services.[10]

7. Norman A. *Rights and risk: a discussion document on civil liberty in old age*. London: Centre for Policy on Ageing, 1981.

8. Wenger C. What do dependency measures measure? Challenging assumptions. In: Phillipson C, Bernard M, Strang P (eds). *Dependency and interdependency in old age – theoretical perspectives and policy alternatives*. London: Croom Helm, 1986.

9. Cornwell J. Health beliefs in old age: the theoretical grounds for conceptualising old people as a group. In: Glendenning F (ed). *Working together for health: older people and their carers*. Stoke on Trent: Beth Johnson Foundation Publications, 1986.

10. Evers H. Old women’s self-perceptions of dependency and some implications for service provision. *Journal of Epidemiology and Community Health*, 1984; **38**: 306–309.

Conservatism and fatalism

Studies of old people’s attitudes to their own health and to health services have tended to be based on samples of old people alone, thus making comparison with other age groups impossible. So similarities between the age groups have tended to be overlooked, and what old people have to say has been interpreted as a consequence of their age rather than any of their other attributes. The standard view of old people that emerges from these studies is that, unlike other age groups, they share a deep-seated conservatism, have low expectations and are fatalistic and ignorant about their own needs.

People of all ages respond positively to survey questions about their health. They say it is good, or normal for their age, that they have no complaints. Sometimes they respond like this because the question seems to imply a comparison with someone else, and without knowing who exactly the interviewer has in mind, they imagine someone whose health is worse than their own. Sometimes they say they are well because they do not want to risk being labelled a hypochondriac or a moaner.[11, 12]

When elderly people say their health is good, however, this has been interpreted as quite out of the ordinary and taken as evidence of their fatalism and low expectations. One recent survey, for example, describes positive answers to health questions as "a common pattern among elderly people" and speculates that this "could be attributed in part to the extent to which people come to adapt to and accept illness and disability, and also the extent to which people may have lowered expectations of good health against which to measure".[13]

Yet almost every characteristic which at one time or another has been singled out as peculiarly significant for elderly people has also been reported in studies of younger people. At every stage of life, for example, people have ideas about what is and is not 'normal' for their age and about the connection between the way they live and their state of health. But if elderly people say they enjoy good health, or that their health is normal for their age, or that they cannot expect good health after the kind of life they have led, it is taken to be age rather than the person who is speaking. This creates a spurious homogeneity in the way others, including health professionals, see them. Grouping them together – 'the over-60s', 'the very old' – is part of the same process. The danger is that we may not only fail to pay attention to the marked differences between them individually and socially, but also miss the similarities between some elderly people and some younger ones.

Conclusion

The professional paradigm of old age is negative in that it marks out old people from the rest of the population, marks them out negatively and suggests that it is their age that is overwhelmingly significant. Stereotypes of any kind are hard to shift and there is unlikely to be any major change in the professional paradigm unless there is a more general public awareness of the negative impacts of ageism.

Nevertheless, a slow shift in attitudes to elderly people is beginning. Old people's organisations are starting to challenge ageism and negative stereotyping.[14, 15] The suggestions for action and guide to resources in the next chapter show how managers and health professionals themselves can start to challenge ageism in the services for which they are responsible.

RACISM

There is little doubt, concludes one recent summary of research, that the NHS presents 'an image of inhospitality' to elderly people from black and ethnic minority groups.[16] Others have been more blunt. Many health and social service personnel do their job precisely because they care about the welfare of their fellow humans, but there is evidence of their cultural arrogance and considerable insensitivity.[17] Although there is generally goodwill towards black and ethnic minority people from members of the caring professions, this is not enough. "Racism pervades the health, social service and voluntary sector".[18]

The extent to which the NHS and its structures have failed to adapt to the needs of a multi-racial, multi-cultural society has been recognised by the National Association of Health Authorities, which has urged a coordinated strategy to ensure that health care is appropriate and equally accessible to all. At the moment, it points out, access may be made difficult by restricted opportunities or inappropriate provision; racial stereotyping may slant assessments of black and ethnic minority individuals and affect the way that staff act, which in turn may lead to lack of confidence in NHS services. There is a lack of integral planning of services for black and ethnic minority groups; instead, 'special' initiatives tend to be funded with short-term resources. Representation of black and ethnic minority communities in health authorities, family practitioner committees and associated training bodies is inadequate. Curricula have been slow to encompass the needs of minority groups. There is a failure to respond to specific health issues – the very high mortality rates from coronary heart disease among Asian men and women, genetic blood disorders among a small but significant number of black people and the disproportionately high incidence of diabetes among

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[11] Blaxter M, Paterson E. *Mothers and daughters: a three generational study of health attitudes and behaviour*. London: Heinemann, 1982.

[12] Cornwell J. *Hard earned lives: accounts of health and illness from East London*. London: Tavistock Publications, 1984.

[13] Itzin C. *Elderly people in the community: screening, support and services*. London: Newham Health Authority, 1986.

[14] Struggles and experiences: older people in struggle. *Critical Social Policy*. Winter 1986/7; 6, 3: 48–57.

[15] Bornat J, Phillipson C, Ward S. *A manifesto for old age*. London: Pluto Press, 1985.

[16] Glendenning F, Pearson M. *The black and ethnic minority elders in Britain: health needs and access to services*. London: Health Education Authority in association with the Centre for Social Gerontology, University of Keele, 1988.

[17] Barker J. *Black and Asian old people in Britain*. Mitcham: Age Concern England, 1984.

[18] Moledina S. *Great expectations: a review of services for Asian elders in Brent*. London: Age Concern Brent, 1987.

West Indians. There is discrimination against black and ethnic minority employees in the NHS.[19]

In this situation, people from black and ethnic minority groups who are also elderly are particularly vulnerable. They face, as one commentator has pointed out, a triple jeopardy, on account of their age, their lack of access to services and discrimination against them.[20]

Black and ethnic minority nurses and doctors are disproportionately represented in hospital geriatric services; they have been actively encouraged to work in them. Although this can clearly bring great benefits to individual elderly patients, the motivation for the encouragement, given the relatively low status of this branch of medicine, has been seen as discriminatory rather than positive.[21] There is no evidence that the services are more appropriate to the needs of black and ethnic minority groups or more flexible because of this pattern of staffing. The danger is that it encourages an assumption of 'second class services for second class patients'.[22]

When it comes to many of the health services with which this report is concerned, however, there is a serious under-representation of black and ethnic minority staff. Very few health visitors are recruited from these groups and there is little effort to attract them. There is in fact some evidence that they are actively discouraged from this work. "You West Indians are hard on your children and you could improve your own values before going into health visiting, or you might inflict them on your clients", one woman applicant was told. Yet 'inflicting' white values on clients from black and ethnic minority groups is something that happens all the time. "You see, even your baby prefers our food to yours!" as one health visitor said to a Pakistani mother. "This herbal stuff", as a GP told a Vietnamese patient, "is all mumbo jumbo".[22]

In a sizeable study in four health districts, over 300 health workers from 14 different occupational groups were chosen specifically because their work brought them into contact with black and ethnic minority patients. Over 80% of this sample was white and 96% trained in Britain. Overall, 60% thought their education about different cultures and different aspects of the health needs of black and ethnic minority people was inadequate. Nurses felt that they needed to know more about the treatment of specific diseases; district nurses – three quarters of whom were white – felt language was a particular problem and that they lacked knowledge of religious and dietary customs.[23] These findings are not perhaps surprising when a study of 10 nurse training schools discovered that where teaching on black and ethnic minority groups was included at all, it occupied a mere two or three hours. One two-year course for community physicians included only one hour on the needs of this section of the population.[22]

In this situation, insensitivity can be expected. Asking to see passports may seem to a health professional to be the quickest way to check family details; it may be both frightening and offensive to people whose sense of security in this country is fragile. Calling out Asian names at a clinic in an accent so incomprehensible to the owners of the names that they sit for hours thinking they haven't been called is unlikely to enhance either confidence or efficiency.[22] Staff who take refuge from their own discomfort and ignorance in 'jokey' references to someone's name, or fail to appreciate the importance of a dietary restriction or religious practice, can be held guilty of racism.

> "However 'innocent' the intent, a black person does not experience expressions of personal racism in isolation. Every black person we know has experienced some form of very overt, hostile racist abuse, whether this be verbal abuse, physical violence or the threat of violence. Underlying the crass racist joke, the petrol bomb and the 'paki bashing' is the same cultural racism. That is why many black people are so angry and so insistent that racism be tackled urgently. That white people often wonder what all the fuss is about is itself a manifestation of cultural racism and insensitivity".[18]

Where knowledge and understanding is lacking, stereotypes may abound. The preoccupation with TB, VD and rickets in health education literature may accord with

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[19] National Association of Health Authorities. *Action not words*. Birmingham: National Association of Health Authorities, 1988.

[20] Norman A. *Triple jeopardy: growing old in a second homeland*. London: Centre for Policy on Ageing, 1985.

[21] Hicks C. Racism in Nursing. *Nursing Times*. Part 1, 1982; **78**: 743–744. Part 2, 1982; **78**: 789–791.

[22] Mares P. Henley A. Baxter C. *Health care in multi-racial Britain*. Cambridge: National Extension College, 1985.

[23] Higham M. *The training needs of health workers in a multi-racial society*. Cambridge: National Extension College, 1988.

certain white notions about the health problems of black and ethnic minority people; they do not accord, for instance, with the concerns of Asian callers to an Asian languages phone-in who wanted to discuss breathlessness, family planning, fertility, psycho-sexual problems, diabetes, nutrition and mental health.[22] The midwife who told her student (in front of an English-speaking Bengali mother) that 'these people all tend to live in overcrowded conditions' was doing her bit to educate the student into not thinking about the structural disadvantage and discrimination that black people face in so many different areas of their lives.[22]

One Birmingham study which found elderly black people to be seriously under-represented on the caseloads of district nurses, found too that these nurses knew less about the life histories of their black patients than their white ones – to the extent of sometimes not knowing who lived in the black household. Their views of their black patients were stereotyped: 'cultural factors foster dependence and low compliance with treatment'.

> "Nurses tended to assume homogeneity among their black clients where there was broad-reaching heterogeneity. In the absence of more enlightened information, it is all too easy for nurses to look to culture for explanation and legitimation in relation to their perspectives on black patients – their understanding of black people's culture being shaped largely by the partial and limited awareness held by society".[24]

'They tend to look after their own'

One stereotype held by these nurses and many others can have particularly far-reaching effects. The idea is widespread that black and ethnic minority people, particularly Asians, have the support of a close and caring family. Certainly elderly Asians in particular may feel strongly that it is the family's responsibility to care for its members.[25, 26] But as we have seen, this aspiration may become increasingly difficult to maintain as more and more black and ethnic minority elderly people live alone or with one other person.

This clearly makes it the more urgent for providers and managers to create community health and other services that are sensitive to the needs of these groups. There is a danger, however, that the stereotype can obscure this need. A vicious circle can be set up: 'the present low take up of services shows that black and ethnic minority people do indeed look after their own so there is no need for us to amend the present shape of services, so low take up continues, which in turn shows that black and ethnic minority people look after their own . . .'

Certainly elderly people from black and ethnic minority groups may reject services that show little recognition of the need for a flexible response to social and cultural differences.[16] Their families may feel that it is their duty to provide for their relatives, especially when any contact with an official bureaucracy is perceived as potential trouble.[18]

Yet in a situation where elderly people from black and ethnic minority groups and their carers lack information about available services it is impossible to discuss whether they have 'chosen' not to use them. As we have seen, there is evidence that where people are informed of services, they express as much willingness as white people to use them. What seems crucial is to discover what people need and how far existing services can help them. It may then be a question not simply of encouraging take up of what is currently on offer, but of developing different services that are more sensitive to cultural expectations and patterns of life.[18] None of this seems likely to happen while the stereotyped notion that 'they tend to look after their own' is unexamined.

Conclusion

Health services are insensitive to the needs of elderly people from black and ethnic minority groups. This amounts to institutional racism which both reinforces and is reinforced by the ignorance and racism of individual health workers. Until recently, there has been a reluctance even to examine these issues. The study of training needs in four health districts quoted above, for instance, was supposed to take six months. In fact, it took 18 because the issue of race was seen as 'too sensitive' by some health authorities, which refused to take part.[23]

24. Badger F. *et al.* Put race on the agenda. *Health Service Journal*, 1988; **98**: 1426–1427.

25. Bhalla A, Blakemore K. *Elders of the ethnic minority groups*. Birmingham: All Faiths for One Race, 1981.

26. Donaldson LJ. Health and social status of elderly Asians: a community survey. *British Medical Journal*, 1986; **293**: 1079–1082.

Yet the situation is changing. Black and ethnic minority groups are making their voice heard. The Standing Conference of Ethnic Minority Senior Citizens, for instance, has strongly challenged what it sees as a "deliberate ploy" in both statutory and voluntary sectors "to do nothing to accomodate the growing number of older people from the black and ethnic communities into the mainstream of service provision". The failure to establish mechanisms for consultation with the emerging 'black' voluntary sector, or to explore the best means of divulging information to the very diverse communities, or to identify local needs, are charges that SCEMSC lays against social services. But its policy recommendations for London boroughs have much relevance to questions of health as well.[27]

At the end of 1988, the National Association of Health Authorities emphasised the need for 'action not words' by government, regional and district health authorities, training bodies and others, to ensure that access to appropriate health care is equitably available.[19] Part Two of this report offers some guidelines and provides resources on which health managers and professionals can draw to make their own contribution to this goal.

[27] Standing Conferences of Ethnic Minority Senior Citizens. *Ethnic minority senior citizens – the questions of policy.* London: SCEMSC. 1986.

GUIDELINES AND RESOURCES FOR ACTION

PART TWO

Community health services are, and will continue to be, crucial to the well-being of very many elderly people at home and those who care for them. How, from the consumers' perspective, can the quality of these services be improved?

The objective of the guidelines in this section of the report is to help people remain at home for as long as possible without putting undue strain on their relationships with their immediate family and friends. To achieve this, services need to be based on four main principles: accessibility; flexibility and coordination; equity; and responsiveness and accountability to consumers.

ACCESSIBILITY

1

The dictionary gives two meanings of 'accessible': "able to be reached or entered" and "open to influence, to the influence of". Both have immediate and equal importance in relations between elderly people, their carers and community health services. This section looks at the first meaning of 'accessible'; the second is discussed under the principle of responsiveness and accountability.

How far a particular service is accessible will depend on the number and magnitude of obstacles in the way of its consumers. In general, obstacles between old people and community health services fall into four categories: buildings and environment; transport; information; referral and appointments systems.

BUILDINGS AND ENVIRONMENT

Managers will want to find out whether their premises pose access problems and call in expert help where necessary to find solutions. They will want to look carefully at both external and internal environments and to pay attention to obstacles in the way of people with disabilities of speech and hearing as well as the more commonly considered ones of sight and mobility. They will consider the widths of openings and the weights of doors; the design of door handles and locks; lighting; the type and condition of flooring; the design and positioning of chairs; access to toilets and the heights of counters and tables.

There is now considerable expertise in making premises accessible to people with different disabilities. A number of organisations are willing to send someone to help with reviews of premises and to collaborate in drawing up detailed proposals for improvements.

TRANSPORT

A review of transport will begin by asking whether old people find it hard to reach services; whether people with specific disabilities have difficulties; how many people are affected and the reasons for their problems.

Solutions will vary according to the size and scale of the problems. They are likely, though, to involve the provision of services to people in their own homes and/or the organisation of transport, possibly jointly between voluntary and statutory organisations.

INFORMATION

Lack of information about services is the most common access problem for old people and their carers. Information about medicines, dental services, chiropody, continence and the use of aids seems in especially short supply. Elderly people who do not speak English – particularly those who cannot read – can have extraordinary difficulty finding out what is available.

Effective dissemination of information is a complicated and lengthy business, and requires an overall strategy. An information strategy will:

- allocate responsibility for the strategy to named individuals.
- specify the different audiences who require information and their particular needs. The two basic audiences, clients and practitioners need to be further refined. Clients, for example, will be divided into women/men, carers who live with/apart from old people, black and ethnic minority groups in each of the above categories. 'Practitioners' will be divided according to professional role and expertise.
- identify what the audiences have in common and where they differ.

- clarify which individuals and staff groups can disseminate information. In addition to practitioners in direct contact with the clients, for instance, clerks in community clinics and GP receptionists have an important role as gatekeepers to services.
- determine the attitudes of key informers to old people and their information needs, and organise training where necessary.
- assemble the information needed by the different audiences.
- consider alternative methods of making information available and decide which is most appropriate for each group. Posters, leaflets and handbooks, local radio stations, audio and videotapes and members of community organisations may all be useful. Seminars and workshops can offer local practitioners the chance to exchange information. A number of community health councils and other voluntary organisations have produced local directories and guides in collaboration with health and local authorities.
- pay attention to the design of printed materials and where necessary obtain professional help with technical details.
- calculate the costs of the strategy and sources of funding.
- evaluate the effectiveness of the strategy.

The Standing Conference of Ethnic Minority Senior Citizens has entered a strong caveat about what it sees as a feverish trend to translate almost everything into 'ethnic languages' for the benefit of older people from the black and ethnic minority groups. Written material in any language, it points out, may be meaningless because these elderly people may not be literate; because there is no guarantee of appropriate follow-up at any given office or institution, which may simply mean further frustration; because these older people need face-to-face interaction if they are to demonstrate their need effectively; and because there are some whose own language – for instance, some Caribbean patois – is untranslatable. "All those first generation elders," SCEMSC concludes, "therefore require direct help from their own communities if they are to overcome the fear, anxiety, frustration, stress, which they experience in attempting to make their needs understood or to gain equal access to essential services".

Age Concern Brent also emphasises the need for direct contact with elderly people from black and ethnic groups. "It is not sufficient to argue that there is no take-up and therefore no need for services. Demand for the services can be generated by providers going out to the communities. This may mean holding exhibitions and stalls or arranging to talk to the communities at religious or cultural festivals . . . Other channels that could be looked into are schools, educating the young about rights and services and using the young as a channel to their older relatives. The possibility of making more use of English neighbourhood classes could also be looked at." Where written material is translated, it must be culturally relevant. One response to a translated leaflet, from the same Brent survey, was "I was reading in Gujarati how English people do things".

REFERRAL AND APPOINTMENT SYSTEMS

Referral and appointment systems are a way of rationing services and it is useful to ask whether they pose unintended obstacles to individuals or groups. Age Concern advocates flexibility in appointments systems in general practice and planning to allow some lengthier appointments for elderly patients. This gives the GP time to explore health problems other than the one the patient is presenting and allows 'opportunistic case finding'. The same principle could be extended to appointments with other members of the primary health care team and to home visits by community nurses. Age Concern, together with the nursing organisations, also advocates direct access to community nurses as an alternative to referral through GPs.

None of this will be of much relevance to elderly people from black and ethnic minority groups if they cannot communicate with their GP and other health professionals. The widespread habit of using family members to interpret has been condemned, especially if it is children who have to participate in intimate discussions about elderly people's health. The common alternative, which involves using other members of staff who happen to speak the relevant language, is also seen as unacceptable, because this is not part of their job and they may not have the necessary skills for the delicate job of interpreting.

There seems little alternative to the recruitment of many more bi-lingual, culturally sensitive staff, together with the expansion of interpreting services. Communication is not, however, simply a question of language. A GP who fails to refer elderly people from black and ethnic minority groups to the community nursing service on the assumption that 'these people look after their own' is failing to understand the nature of individual needs. Some ways of helping staff to overcome failures in communication are discussed later under the heading 'challenging racism'.

ACCESSIBILITY: RESOURCES FOR ACTION

Buildings and environment

- **Centre on Environment for the Handicapped.** CEH provides a specialist information and advisory service on the environmental needs of all handicapped people. Its aim is to encourage environments which enable them to make the most of their lives. Its information and consultancy service will tailor advice to specific circumstances and needs. CEH, 35 Great Smith Street, London SW1P 3BJ. Tel 01-222 7980.

- **Access for Disabled People: design guidance notes for developers.** This 1985 report by the Access Committee for England, published by the Centre on Environment for the Handicapped, offers practical guidance on how to change external and internal features of buildings to make them more accessible.

- **Access for All: design notes to improve access for the disabled.** Middlesborough Borough Council's 1984 guide to improving access to buildings is a particularly comprehensive one of its type. It is available from Department of Planning and Architecture, Vancouver House, Gurney Street, Middlesbrough TS1 1QP. Tel 0642 245432 x 3774.

- **Access projects and officers.** Some local disability organisations have access projects or officers who can give expert advice on improving access to public buildings. In North London, for example, the Islington Disablement Association sponsors the Access Project, 49–59 Old Street, London EC1V 9HX. Tel 01-608 1949.

  The Haringey Disablement Association manages a similar access project, with an officer who is funded by the local authority. Access Officer, Haringey Disablement Association, Tottenham Town Hall, London N15 4RY. Tel 01-885 2760.

  To find out if there are similar organisations in your local area, contact the local authority and local voluntary organisations for people with disabilities.

Transport

- **Door to door: a guide to transport for disabled people.** The third edition of this comprehensive guide to benefits and services was published by the Department of Transport in 1989.

- **Going Places: two experiments in voluntary transport.** This publication by R Hedley and A Norman (1984) from the Centre for Policy on Ageing includes a useful guide to sources of information on community transport and a discussion on managing a voluntary transport scheme. Centre for Policy on Ageing, 25 Ironmonger Street, London EC1. Tel 01-253 1787.

- **Chance or choice? Community care and women as carers.** This publication by the Greater London Council Women's Committee and Health Panel (1984) includes a useful checklist of access problems and some solutions.

Information

- **In the picture with Age Concern.** This is the title of Age Concern's campaign to meet the information needs of elderly people.

They have produced leaflets for retired people to guide them to information sources, which are available from Age Concern England, Information and Policy Department, 60 Pitcairn Road, Mitcham CR4 3LL. Tel 01-640 5431.

- **Information needs of the elderly.** This report, commissioned by the DHSS from the Research Institute for Consumer Affairs, and published in 1980, analyses the information needs of different sections of the older population. It evaluates the effectiveness of the various media in getting information across and describes the methods that elderly people themselves prefer.

- **Hackney Pensioners Health Handbook.** This guide to services for pensioners by City and Hackney Community Health Council is an excellent example of a comprehensive handbook for service users in one district. It is available from City and Hackney CHC, Shoreditch Health Centre, 210 Kingsland Road, London E2 8EB. Tel 01-739 6308.

Referral and appointment systems

- **Meeting the needs of older people: some practice guidelines.** This 1986 publication from Age Concern includes advice on improving access to primary health care teams. Available from Age Concern, as above.

- **The role of the receptionist in general practice.** This is the title of a useful article by S Arber and L Sawyer published in the journal *Social Science and Medicine* in 1985 (**20**, 8: 911–2). It gives guidance on improving appointment systems from the patient's perspective.

FLEXIBILITY AND COORDINATION

2

To health service managers and practitioners, 'coordination' and 'flexibility' probably have to do with structures and organisation. The concerns of people who use services are usually rather different. Their interest in coordination has to do with issues like whether transport arrives at the expected time; whether or not they have to choose between time in a day centre and a visit from the chiropodist; whether they have to repeat the same information about themselves many times to different people. To them, flexibility is about whether they have a say in the time of day that people visit them and what they can ask of them. Finding out just what visiting professionals are there for may be particularly hard for elderly people from black and ethnic minority groups.

A large number of innovative and experimental community care projects have been established around the country in the past decade, some by a single agency, others with joint funding. The projects vary in size and in the levels of need they try to meet. But a consensus seems to be emerging about the approach that is most successful in discovering clients' perceptions of their needs and planning appropriate services. The basic elements of this approach are getting to know the client; individual care plans; and keyworkers.

GETTING TO KNOW THE CLIENT

Getting to know the individual client is implicit in much of the initial work of taking case histories and making assessments. But the practitioner's aim is usually to make an objective needs assessment, or to screen, rather than to get to know the client personally. Very many old people have repeated the same facts about themselves and their situation to a number of different professionals without feeling that any one of them has 'got to know them'.

The new thinking in community health services makes the process of getting to know the client explicit and emphasises the value to both the client and the service of one person doing this. Two health authority projects have explored this process in depth: the Getting to Know You project in North Manchester and the Care of Elderly People at Home project in Gloucester.

Getting to Know You was pioneered in a psychiatric hospital with long-stay patients who were about to move into the community. It was described as "an individualised approach to service planning", the aim of which was to encourage service providers "to think again about traditional practices and service organisation from the point of view of those who use the service". Later, it was taken up by a multi disciplinary study group on services for elderly people in North Manchester; it was then combined with a number of imaginative ways of researching needs for care in the community, including the gathering of local community histories and 24 hours of participant observation in a residential home for old people.

Getting to Know You is described by the Manchester group as an "individual needs assessment" that is "in many ways . . . very different from what professionals would normally consider to be assessments". The explicit intention behind the method is to "strip staff of their 'professional' assumptions and allow them to feel again the raw experience of the lives of those who use the service". This is seen as a necessary part of the enterprise, because "undoubtedly, over a period of time we create barriers to shut off what we don't want to see, and our needs become confused with those of our clients. For us to get to know a client, not as a service receiver but as just another person, helps to break down barriers and clarify the needs of clients".

Conventional assessments require professionals to make an objective judgement about clients, from whom they deliberately distance themselves. Getting to Know You, in contrast, requires the assessor to think of the client as "just another human being" and "to use the knowledge we all have as humans to make judgements about what that person needs". The actual practice was barely formalised in Manchester, involving an interview based on a simple list of guidance notes. In the psychiatric hospital, members of staff got to know one or two patients on a long-stay ward. In the work with old people, each member of the study group got to know one old person by spending time with them at home, and used the knowledge they gained to generalise more widely.

Getting to Know You in action

Mrs A, aged 75, is severely disabled, unable to walk or speak and needing intensive help with personal care. She is cared for by an only daughter in her forties who lives in a neighbouring flat.

- *who is this person? their likes/preferences/skills/personality?*
- *their relationships? extent/quality*
- *life history? major life events and experiences?*
- *extent of involvement with and impact upon of services in the past?*
- *present circumstances? how spend time/with whom/ doing what?*
- *specific ways in which disability complicates life? mobility/self-care/ communication/ interaction/ physical survival?*

Through getting to know both mother and daughter – using the interview guidance notes above – the project worker discovered a history of worsening confusion stretching back over 20 years, during which the women received very little help from outside agencies, for which the daughter had had to struggle, and a great deal from their informal network.

The outcome of the Getting to Know You process was a list of previously unidentified needs which served the health and local authorities as the basis of a joint plan of care. Here is an extract from the list:

MOTHER needs

- *existing relationship with daughter and neighbours protected, and perhaps to develop new ones.*
- *to know she can stay where she is even if her daughter can't care for her.*
- *a less threatening physical environment.*

DAUGHTER needs

- *to have needs and wishes better understood.*
- *someone to talk to about the past.*
- *to be sure safeguards for mother don't rest solely with her.*
- *freedom to pursue other relationships and interests.*

NEIGHBOURS need

- *not to feel they have failed this family.*

The next stage was to prepare a list of needs to be negotiated between the daughter and a single professional with whom she got on and who acted for the others. That professional became a keyworker, negotiating with others on the daughter's behalf to secure for her and her mother: financial help and advice on benefits; advice about and provision of aids and adaptations; help with transport; physiotherapy and occupational therapy; emotional support and counselling; respite care; help during the day and at night.

The Gloucester Care of Elderly People at Home project uses a 'biographical method' which is not unlike the Manchester approach. Three 'care coordinators' based in primary health care teams begin their work with old people referred to them by other members of the team by doing a biographical interview. This provides the basis of an analysis of need which, in turn, becomes the basis for a contract of care. The biographical interviews are open-ended and exploratory, although the care coordinators have more preparation and more help than the Manchester workers. A checklist reminds them of the basic rules for biographical interviewing – 'keep the interview as much like a conversation as possible; be an attentive listener rather than a Robin Day anxious to shoot your own questions'. An assessment schedule outlines the biographical territory to be explored, from childhood and family of origin and school and education to present circumstances, health and dependency in retirement.

Both Getting to Know You and the 'biographical method' recognise and accommodate the uniqueness of individuals. Both offer the possibility of treating old people sensitively and flexibly and take on board the need to tailor intervention according to its likely impact on an individual's sense of self and feelings about dependence. Both allow a careful balance between the individual's right to self-determination and the risk to themselves and others.

Yet both also pose some difficulties. Both are diametrically opposed to the way in which most professionals have been trained to work with clients and so may threaten them. In Gloucester, the research team describe the phenomenon of the 'instrumental imperative' – the feeling among professional care workers that they must 'do something' for people to validate their involvement with them. This undermines the lengthy and subtle business of getting to know someone personally, and workers need to be supported in the new approach.

The overall response of the professionals involved in the projects in Manchester and Gloucester has, however, been positive. Both projects claim that 'getting to know the person' changes professional attitudes towards clients in a fundamental and lasting way. In Manchester, the project has led to the development of three new principles of service planning: the need for continuity in people's lives; the need for choice; the need for people to have control over decisions that affect them.

INDIVIDUAL CARE PLANS

Individual care plans construct 'packages' of services tailored to specific individual needs, rather than assuming that clients must accommodate themselves to one standard way of receiving services. A plan can be drawn up by one professional or by a case conference that involves representatives of a number of agencies, but in either case the plan must be negotiated and agreed with the client and, where appropriate, the client's carers. Once a plan has been agreed, responsibility for implementing and monitoring it rests with one named individual, who may or may not be the keyworker (see below).

In a few projects, the keyworker with overall responsibility has a budget for buying in goods and services identified in individual plans and not routinely provided by statutory or voluntary services. These may include, for instance, kettles that switch themselves off, automatic washing machines and clothes dryers. In the Community Care Project in Kent, they include help at the time of day that statutory services are not geared to cover – early morning, late evening, mealtimes – as well as therapeutic activities, like help with managing phobias.

One of the more innovative aspects of individual care plans is their assumption that services can be provided at times of the day or week that suit the client. In Kent, project workers have developed a simple 'solitude assessment chart' which sets out the days of the week in daytime and evening sections. The person drawing up the care plan marks every time of day and day of week when the client sees carers, friends or professional workers. This shows at a glance where there are gaps that may need filling and allows the delivery of service to complement rather than compete with informal contacts.

In Newham, where Age Concern runs a project to care for elderly mentally frail people at home, the entire individual care plan budget is spent on employing support workers for individual clients, who provide the variety of domestic and personal care considered necessary.

By its nature, each individual care plan will be unique. But all share certain basic elements. An individual care plan

- springs from an assessment of individual needs that takes account of their social and personal context.
- describes a package of services from statutory and voluntary sources that meets the needs of both client and carer.
- is drawn up by practitioner(s) and negotiated and agreed with client and carer.
- may have an attached budget.
- is implemented by a named person who also has responsibility for its monitoring and evaluation.

KEYWORKERS

Most domiciliary and community care schemes for elderly people employ people described as 'keyworkers', but there is no uniformity in what they actually do. They may be case managers, care coordinators, care workers or support workers. Some are 'key' to the client, but others are 'key' to the organisation.

To the client, the keyworker needs to be someone with whom it is possible to have a personal relationship and who will act as a link with other services and the outside world. The official role is important – the keyworker could be the home help, social worker, district nurse, health visitor or care coordinator. What matters is that there is one person who will explain who does what and when and why services are needed; who will negotiate with those services on the client's behalf; and who acts as their advocate if necessary.

To the organisation, the keyworker might be the person who makes the initial assessment of the client and draws up, or helps to draw up, the care plan. The keyworker might conduct reviews of the care plan and call and chair case conferences about the client. They might hold the budget attached to the care plan, make referrals to other professionals and oversee the work of all those who contribute to carrying out the plan.

When a term like 'keyworker' becomes widely used and starts to encompass a number of potentially conflicting meanings, it is important to make explicit what it means in any one context. Otherwise the interests of the more powerful party in the relationship are likely to prevail. The qualities and skills needed by client and organisation keyworkers may be different too: the first needs to spend a great deal of time with a small number of elderly people, while the second needs to have enough authority to command the respect of professionals in other services, and enough seniority to hold a budget. So it may not be appropriate for one person to be both client and organisation keyworker; it might be better if the latter were the former's manager.

FLEXIBILITY AND COORDINATION: RESOURCES FOR ACTION

Getting to know the individual

● **Getting to Know You.** Two reports describing the Manchester project were published in 1986. Getting to Know You: a reflection and review of an individualised approach to services planning, and All our Futures: a working party report on services for elderly people in North Manchester. They are available from Mrs R G Robinson, Sub-Unit Manager, Mental Health Unit, North Manchester Health Authority, Central Drive, Crumpsall, Manchester M8 6RL. Tel 061-795 4567 x. 2826.

● **The Gloucester Care of Elderly People at Home Project.** This research and development project, run jointly in Gloucester Health Authority by the Open University Department of Health and Social Welfare and the Policy Studies Institute, has been carefully documented in a series of project papers. Of particular relevance are:

– *Care for elderly people in the community: a review of the issues and the research* (Project Paper 1) by M Carley *et al.* (1987) which explains the background and collects together all the relevant research.

– *Identifying, assessing and monitoring the needs of elderly people at home* (Project Paper 2) by M Carley *et al.* (1987) which explains the work of the care coordinators and examines some conflicts in their role.

– *A biographically based health and social diagnostic technique: a research report* (Project Paper 4) by M Carley *et al.* (1988) which describes in detail the biographical method of interviewing and the care coordinator's experience of using it.

All the papers are available from Professor M Johnson, Department of Health and Social Welfare, The Open University, Milton Keynes. Tel 0908 274066.

Individual care plans

- **In Kent.** The Kent Community Care Scheme is fully documented in two reports by D Challis and B Davies: *Case management in community care and Matching needs to resources*, both published by Gower in 1986.

- **In Newham.** This 'dementia home support project' was funded for its first three years (1986–9) by the local health authority and social services department. The development officer and research coordinator for the initial pilot phase was Dr Janet Askham, Age Concern Institute of Gerontology, King's College London, 552 King's Road, London SW10 0UA. Tel 01-872 3035. The project has now been taken over by Newham Health Authority. The project officer is Catherine Fonque, Dementia Home Support Project, Plaistow Hospital, Samson Street, London E13. Tel 01-472 1580.

- **In the inner city.** Another approach to individual case plans and case management is described in *The case manager project: report of the evaluation* by D Pilling published in 1988. It is available from Rehabilitation Resource Centre, Department of Systems Science, City University, London EC1. Tel 01-253 4399.

Keyworkers

- **Keyworkers for elderly people in the community.** This is the title of project paper 6 in the Gloucester series (see above) which discusses the concept of the keyworker and its application in different projects around the country. It is available from Professor M Johnson, address as above.

Other innovative projects

- **Community Care Project – Darlington.** This project provides health and social care for elderly people at home as an alternative to long-stay hospital admissions. It has been running since 1984 and won a Health Management Award in 1986. Two articles in the *Health Service Journal* (27.5.86 and 2.7.86) describe it in more detail. This is also one of a number of innovative projects included in *Cumberlege in Action*, a directory of good practice that influenced the Community Nursing Review Team, published by the King's Fund Centre in 1987. Dr. Malcolm Stone, the project manager, is at Project Office, Regent House, Commercial Street, Darlington DL3 6JG. Tel 0325 460571.

- **Triple jeopardy: growing old in a second homeland.** This book by Alison Norman analyses the problems faced by older people who have come from different countries to settle in the UK and gives details of innovative community projects that are trying to respond to their needs. Many of these are of particular interest to people who are trying to enable elderly people to remain in their own homes with the maximum comfort. Examples are the Harlesden Community Care Project, which uses Afro-Caribbean volunteers to provide personal personal care in the home; the Foleshill Family Centre in Coventry which has tried to recruit Asian and Caribbean as well as white home helps; and the meals service provided by Brent, the first borough in the country to give equal attention to the dietary needs of elderly people who are Jewish, Afro-Caribbean or Asian. The book is published by the Centre for Policy on Ageing and can be ordered from Bailey's, Warner House, Folkestone, Kent CT19 6PH.

- **Meeting the needs of older people from ethnic minorities: local authority initiatives.** This report of a conference followed up *Triple Jeopardy* and is also published by the Centre for Policy on Ageing. It can be read at the CPA Library at 25 Ironmonger Street, London EC1. Tel 01 253 1787.

EQUITY

3

If equity has its dictionary meaning of fairness, lack of discrimination and equal opportunity, then community health services do not treat elderly people equitably. Elderly people from ethnic minorities are often seriously under-represented among users of these services; the services may be unadapted to their needs. More generally, the tendency has been to concentrate resources on people who live alone or who have no one to care for them, in the hope that those with carers can be left to their good offices. This seems fair, because nearly everyone gets care of some sort. But in fact objectively equal need attracts different levels of service, according to whether the elderly person has a carer or not. And the work that carers do is often included in the needs assessment without their own needs being considered.

Any policy that really aims to achieve an equitable matching of needs and services will make an explicit commitment to meeting the needs of carers as well as of people considered 'at risk'. The commitment to carers will be reflected in both the initial assessment of needs and the individual care plans.

A strong case has been made for targeting services towards households where carers are looking after very frail old people. But this has had little impact on service provision. Meanwhile, the search for unmet need among elderly people continues and the extensive literature on screening and case-finding continues to expand. Preventive health care is of course important. But it is nevertheless remarkable that the discovery of unmet need should have been the focus of so much debate at a time when needs that are already well-documented are still not being met.

A STRATEGY FOR WORKING WITH CARERS

A strategy for working with carers has four fundamental elements: protection of relationships; provision of information; provision of household help; and provision of respite.

Relationships

People who work with carers emphasise the complexity of their feelings. Only a minority of carers positively choose this role; the majority become carers with feelings of obligation and resentment as well as loyalty and affection. The relationship between the carer and the person they care for is both intense and fragile; dislike and even hatred can be mixed with deep feelings of responsibility and love, and a desire to protect the dependent person from 'less caring' others, including professional workers.

The protection of the bond between carer and dependant should be the yardstick against which needs for professional support and care are assessed. The bond needs to be given positive recognition and to be protected from the damage that can result from the very hard work and stress that caring for a frail old person entails.

Information

Carers need information tailored to their own needs as well as those of the person they are caring for. They need information particularly about benefits and aids and adaptations that may be useful to them.

Household tasks

Caring for a very disabled old person can take up every available hour and carers often need help in house and garden, and with repairs and redecorating. Assistance of this sort can help to reduce stress and so enable the caring relationship to be sustained for longer; it should be included in the plan of care for the household. Although statutory authorities are rarely equipped to provide this sort of help, liaison with voluntary organisations may help them to find it.

Respite

Carers need respite from their 24-hour responsibility at regular and predictable times. They may need frequent short breaks during the day, relief at night, and a day or days away. Statutory authorities may need to collaborate with voluntary agencies to provide this range of help.

Where respite care is provided for the dependent person away from their own home, it must be acceptable to the carer as well as the elderly person. Carers often feel great guilt and anxiety when they leave their dependant in the care of other people and the respite will offer them no relief if they feel that their dependant is not being properly looked after. Whenever possible, it is better that respite care is provided in the dependent person's own home; failing that, it is helpful to introduce them to the new setting before they move there.

People referred by the consultant psycho-geriatrician to the Family Support Unit in Middlesborough, for instance, go there on two days a week for a few weeks before they spend a night there. With five beds and ten day places, the unit can offer a week's respite every six or seven weeks to 36 people. During this week, carers can come to a support group which increases both their confidence in the unit and the relief they gain from this period of rest.

The Middlesborough Unit reckons that a similar facility is needed for every 150,000 population. It costs slightly more than providing simply five psycho-geriatric beds and 10 day places, but "it meets the needs of the carers in ways which are not fully met solely by day care and respite care in hospitals or residential homes".

EQUITY: RESOURCES FOR ACTION

● **The King's Fund Carers Unit.** This unit was set up in 1986 to help carers receive greater recognition, more practical support and better information about the services available; it consults widely with carers and their organisations. The unit has a full publications list of handbooks for carers, guidelines for workers in health and social services and voluntary organisations, and training packs. Titles include:

– *Carers: a video assisted workshop for primary health care professionals.*

– *A new deal for carers* by Ann Richardson, Judith Unell and Beverley Aston. This draws together ideas and experiences of how to provide better services for carers from many different agencies, and is relevant to staff at all levels.

– *Caring at home* by Nancy Kohner. This comprehensive handbook brings together information and advice relevant to all carers and covers help in the home, money and legal matters, time off, carers' feelings, support groups and where to go for help.

– *Caring together* by Judy Wilson. This is a practical guide to setting up and running groups for carers.

– *Carelink.* This Newsletter, published three times a year, includes reports of projects around the country, notices of meetings, and discussions of policy.

– *Work with black and ethnic minority carers.* The King's Fund Carers Unit recognises that black and ethnic minority carers may experience racism, isolation, inappropriate services and barriers to communication, and part of its programme is concerned specifically with their needs.

– *Asian carers/Niradharoki dekhbhal* is a video for Asian carers in Leicester, made by Voluntary Action Leicester and SCOPE, an agencythat cares for elderly Asians in the city. In the video, carers talk about their experiences of looking after their relatives and the services they use. There are two versions, English and Hindi, and the accompanying booklet, which describes locally available help is available in Gujarati, Urdu, Punjabi, Bengali and English versions. From Voluntary Action Leicester, 32 de Monfort Street, Leicester LE1 7GD. Tel 0533 555600.

Other work by the King's Fund Carers Unit includes information for carers of elderly Asians and a project for people looking after elderly Afro-Caribbeans, run by the West Indian Women's Association in the London borough of Brent; publications will be available in 1990. The King's Fund has also supported work by the Standing Conference of Ethnic Minority Senior Citizens and Help the Aged; Birmingham City Council's Community Care Special Action Project; and the National Self Help Support Centre (starter grants to black carers' groups).

Further information from Carers Unit, King's Fund Centre, 126 Albert Street, London NW1 7NF. Tel 01-267 6111.

● **The Association of Crossroads Care Attendant Schemes.** This nationwide network of schemes to support carers at home has amassed considerable expertise on carers' needs, including that for respite care. The national office is at 10 Regent Place, Rugby, Warwickshire CV21 2PN. Tel 0788 73633.

● **Middlesbrough Family Support Unit.** Details of this respite care scheme for elderly mentally ill people are available from The Coordinator, Family Support Unit, 5 Eastbourne Road, Middlesbrough, Cleveland TS5 6QS. Tel 0642 820000. There is also an account of the scheme in *Carelink* (No 2, Summer 1987) which is available from the King's Fund Carers' Unit, as above.

● **Chance or choice? Community care and women as carers.** This report by the GLC Women's Committee and Health Panel (1984) provides a useful checklist for health authorities wishing to plan and evaluate support to carers.

4

RESPONSIVENESS AND ACCOUNTABILITY

There is no single way to make health services responsive to the needs of elderly people, especially because they are a relatively powerless group of patients. Any strategy to make health services more responsive and accountable to elderly users will have three main planks: combating ageism; combating racism; and enhancing elderly people's power as consumers – both as individuals and as a group.

CHALLENGING AGEISM IN HEALTH SERVICES

Health professionals have the power to influence attitudes towards old age and elderly people because of the special credence that is given to their views. But if they are to help improve public attitudes, attention needs to be given to both their training and their professional practice.

Ageism awareness training can help people become more sensitive to their own responses to old people. So can training sessions in which elderly people discuss what it is like to be patients.

It is not easy to change relationships between professionals and patients, or to alter routine professional practice. But there are ways of working that can help to raise professional awareness of the patient's individuality and right to be involved in his or her own treatment and care. These factors can be very easily forgotten, particularly when working with old people who are mentally frail or physically dependent.

The Lambeth Community Care Centre is a small community hospital in South London, to which patients are referred for acute illnesses, respite care or terminal care. Its philosophy is to make the patient's experience of being in hospital as much like being at home as possible. Medical supervision is provided by the local GPs.

Patients in the centre have charge of their own notes and their drugs. They, and if they wish it their visitors, are free to write in the notes; if a member of staff wishes to see the notes they have to ask the patient's permission. Equally, if a staff member wants to change a patient's drugs, they must discuss this with them; because the patient holds the drugs, it is up to the staff to make sure that they understand the regime. Almost unavoidably, these ways of working force the professionals into an awareness of the patients' individuality and right to be involved in decisions that affect them.

CHALLENGING RACISM IN HEALTH SERVICES

The ethnocentricity of community health services has been evident throughout this report. Staff in those services, as we have seen, feel hampered by their ignorance of the cultural backgrounds and health needs of elderly people from black and ethnic minority groups. Stereotyped views among staff contribute to the failure to meet needs. Any programme to combat the racism which taints community health services will start from two premises. First, the commitment by senior management, expressed by clear designation of responsibility, to services which are equitable in staff employment and service delivery. Secondly, the involvement of community groups in helping to achieve racial equality and in building services which are culturally sensitive. Training for staff at all levels – and for members of health authorities as well – will be systematic and continuing.

To challenge racism, however, whether in individuals or in the structure of services, is not simple. One comment on the needs of Asian communities has also a wider relevance: "It is not sufficient to know of the cultural practices of the various Asian groups. Respect and appreciation must be shown that these practices are absolutely valid and central to the person's everyday way of life." It follows then that even with a policy of employing Asian people to fill certain posts, linguistic compatibility with the local community is by no means the only criteria for selection; a certain empathy and understanding of life experiences and expectations must be shown.

> "A member of staff fully conversant with cultural practices can still hold deeply instilled racist beliefs and attitudes. Anti-racism training, which must be on-going, is presently virtually non-existent in the Health Services . . . partly due to a shortage of suitably qualified trainers. The current practices employed in a number of area offices of asking black staff to train fellow colleagues, simply because they are black, has put these very members of staff in an uncomfortable position of not being able to state that they do not wish to adopt the trainer's role because trainers they are not. A black member of staff may find intolerable pressures put on him or her 'to find answers on all issues relevant to black people'. S/he legitimately would, like white colleagues, have an interest in some issues and not in others."

To avoid the difficulties described above, initiatives on anti-racism should be carefully planned. Finding local contacts and resources is often a useful starting point. Discuss your ideas with black and ethnic minority community groups with whom contacts have already been established. The local community relations council may be able to provide help. Local trade unions have an interest in anti-racism and equal opportunities. Some districts have bought in help from specialist training organisations, which organise courses and provide experienced trainers. The NHS Training Authority has recently produced a directory of training materials and training organisations for equal opportunities and anti-racism.

ENHANCING CONSUMER POWER

Making sure that services are responsive to individual patients and that their wishes are known and respected means altering the balance of power between professionals and patients. Any strategy to enhance the power of individuals as consumers will ensure that they are helped to make their wishes known.

Finding ways to make health services accountable to their consumers as a group is a considerable challenge – the more so when the consumers are comparatively poor and powerless. Any effort in this direction needs to be adequately resourced.

Community health councils and local organisations that represent the interests of elderly people may offer a basis from which to work towards the establishment of health care associations relating to particular health centres and clinics, or services in a particular area. Within an association, a gerontology forum may focus particularly on the needs of local elderly people. Both associations and forums offer consumers the opportunity to meet professionals and service providers. From this starting point, local advisory groups can be established which give consumers the chance to become actively involved in decision-making.

In some circumstances, a community health development worker may be an important appointment, particularly where many small organisations need to come together or where specific groups – like people who are housebound, or carers, or members of black and ethnic minority groups – need special support if their interests are to be properly represented. The community health development worker needs resources that include adequate secretarial and administrative support. This work cannot be done on the cheap or by someone who has a multitude of other responsibilities.

In Haringey Health Authority, an ethnic minorities development worker was appointed for three years from 1985, financed by the King's Fund. The appointment was subsequently extended for one year and is now an established post. The aim was to help others to 'develop systems and approaches which recognise and are adapted to the district's multi-racial population'. The worker's brief covered developing policies for equal opportunities in employment; service provision; planning; training and education for health authority members, managers and staff; and the provision of advice and information on health services to community organisations.

As part of the initiative to improve service provision the post of health worker for black and ethnic minority elderly people was created in the community nursing services. A health visitor was appointed in 1986 and her task has proved complex.

Difficulties have been posed by the diversity of language and cultural groups to be covered; the worker's inexperience of working with community organisations; and lack of access to the hospital sector.

Another development was the setting up of the Black and Ethnic Minorities Elderly Forum as a sub-group of a new health and local authority joint planning team for the elderly. It is chaired by the health authority's service manager for the elderly and includes representatives from black and ethnic minority community organisations. The 'forum' model, pioneered by the Haringey project, provides a way of involving black and ethnic minority groups directly in reviewing and planning services. Its effectiveness has yet to be assessed, and the benefits and constraints are likely to become clearer as the process of participation in service planning develops.

RESPONSIVENESS AND ACCOUNTABILITY: RESOURCES FOR ACTION

Challenging Ageism

- **Consumers as educators.** Some pensioners' groups and community health councils are interested in teaching professionals what it is like to be on the receiving end of services. Contact your local groups and CHC to see whether this would interest them.

At St George's Hospital Medical School in London the geriatric department arranges for second year medical students to spend time with elderly people in their own homes, getting to know them and to understand their point of view. Further information from Professor Peter Millard, Geriatric Department, St George's Hospital Medical School, Cranmer Terrace, London SW17. Tel 01-767 5536.

- **Ageism and awareness.** A package of training materials for 'paid carers' in health and social services based on a positive model of ageing is *Training and education for an ageing society* by C Phillipson and P Strang. It is designed for in-service training with community nurses and can be relatively easily adapted for paramedics and others. Unfortunately now out of print, it is available in the libraries of the Health Education Authority and Centre for Policy on Ageing. HEA, Hamilton House, Mabledon Place, London WC1. Tel 01-631 0930. CPA, 25 Ironmonger Row, London, EC1V 3QP. Tel 01-253 1787.

– *Ageism awareness training: a model for groupwork* by C Itzin, gives an account of ageism awareness training and includes a programme to guide trainers in this sort of work. It is a chapter in *Dependency and interdependency in old age: theoretical perspectives and policy alternatives* by C Phillipson, M Bernard and P Strang, published by Croom Helm, 1986.

- **Consumers as partners.** *No place like home* by Gillian Wilce describes the setting up and operation of the Lambeth Community Care Centre. Published by Bedford Square Press in 1988, it can be ordered from Harper and Row, Estover Road, Plymouth PL6 7PZ. Tel 0752 705251.

– *User friendly services* by Liz Winn and Allison Quick gives managers of community health services guidelines for developing user-centred services. It draws on detailed material from developments that have already taken place in the NHS and offers practical advice about getting started. Some of the common pitfalls are explored and the book includes a discussion of the particular problems associated with consumer surveys. Managers are urged to think carefully about the type of developments they want to establish – from consulting users periodically, through to structured attempts to involve users in decision making and service planning. Published by the King's Fund in 1989, copies can be ordered from Bailey's, Dept D/KFP, Warner House, Folkestone, Kent CT19 6JP.

– *Taking the initiative* is a short article describing general practices in Birmingham and South London which allow patients to read their notes while waiting to see the doctor. Published in *Health and Social Service Journal*, 27.2.86.

Challenging racism

● **Health and social issues in multi-racial Britain.** This series from the National Extension College includes 18 different titles, designed for health care workers and/or trainers and policy makers.

– *Health care in multi-racial Britain* by Penny Mares, Alix Henley and Carol Baxter is a comprehensive handbook which explores key issues in developing appropriate health services and is designed for health care workers.

– *Providing effective health care in a multi-racial society: a checklist for looking at local issues* is intended for health authorities and health workers, and aims to promote direct consultation between authorities and black and ethnic minority communities.

– *The right to be understood* by Jane Shackman, Jill Reynolds, Stewart Greenwell and Rose Chin is a video training package which shows the problems that can arise in situations where interpreting is needed and enables viewers to compare the approaches used when finding an interpreter, preparing for an interview and debriefing.

– *Equal opportunities in the NHS: a checklist* by Maggie Pearson.

All these materials are available from National Extension College, 18 Brooklands Avenue, Cambridge CB2 2HN. Tel 0223 316644.

– *Equal opportunities: a training and resource pack* has been produced by the NHS Training Authority to support the development and implementation of equal opportunities initiatives. It is available from NHS Training Authority, Avon Direct Mail, Old Mill Road, Portishead, Bristol BS20 9EG.

● **Consumer experiences.** Interviews with elderly consumers reported by Shabira Moledina in *Great Expectations: a review of services for Asian elders in Brent* give an often poignant picture of what it is like to be on the receiving end of service provision. As one woman said: "We are human beings also. We have two eyes, two arms and two legs. Are our needs that drastically different that you always have to do special work on us? ... We are the community, we are not separate from it, living somewhere where no one can reach us. They only need to keep their eyes and ears open, this is all we ask from them". The report is available from Age Concern Brent, 120 Craven Park Road, London NW10 8QD. Tel 01-965 7711.

– *Race, Health and Welfare* is a comparative study of the experiences of health and social services among Afro-Caribbeans, South Asian and UK-born white people in central Bristol. It includes some vivid descriptions from the users themselves of how the different services appear to them – and shows particularly how lack of a common language can hamper the effectiveness of provision. It also brings some sad accounts of loneliness among these ageing populations. The report is published by the University of Bristol (1984) and is available from Dr C S Fenton, Department of Sociology, University of Bristol, 12 Woodland Road, Bristol BS8 1UQ. Tel 0272 738455.

Enhancing consumer power

● **Health Enhancement.** This is the title of a directory of projects for older people by C Cloke. It describes different ways of providing elderly people with information about health, health services and medicines. It includes, for instance, information on pensioners' health forums and health days and festivals, on a foot health project and on a stroke club. Published by Age Concern England (1985), it is available from The Information Department, Age Concern England, 60 Pitcairn Road, Mitcham, Surrey CR4 3LL. Tel 01-640 5431.

● **Age Well Ideas Pack.** This pack from the Health Education Council and Age Concern aims to encourage people to take account of changing health needs among elderly people and to get more activities and groups going. Its pull-out sheets and publication lists give a picture of the range of health interests and ideas among elderly people. It is available from Age Concern England (see above).

● **Positive health skills for older people.** Three reports published in 1985 and 1986 describe and evaluate a community-based approach to health education for elderly people which aims to equip them to recognise their own health needs and then take action. They are available from Bradford and Airedale Health Promotion Unit, 2nd Floor, Joseph Brennan House, Sunbridge Road, Bradford, BD1 2SY. Tel 0274 307601.

- **Challenging the myths.** This review of courses and talks for pensioners emphasises how they themselves can organise them, with health professionals and community workers in support. Published by the Agewell Campaign in 1987, it is available from Agewell Campaign Unit, 60 Pitcairn Road, Mitcham, Surrey, CR4 3LL. Tel 01-640 5431.

- **The Whittington Centre.** This centre for elderly people has employed a community development worker to help establish a local advisory group, in an area with relatively few community organisations and a large black and ethnic minority population. Further information from The Whittington Centre, Rutford Road, Streatham, London SW16. Tel 01-677 7415.

- **The Haringey experience.** A report entitled *Working toward racial equality in health care* by Nirveen Kalsi and Pamela Constantinides gives a detailed account of the experience of the ethnic minorities development worker and the further innovations that came from this three year project in Haringey Health Authority, including the setting up of the black and ethnic minorities elderly forum. It is published by Haringey Health Authority and the Primary Health Care Group at the King's Fund Centre and is available from King's Fund Centre, 126 Albert Street, London NW1 7NF. Tel 01-267 6111.

- **Standing Conference of Ethnic Minority Senior Citizens.** This umbrella organisation brings together retired members of black and ethnic minority groups in the Greater London area. The idea for such an organisation was first voiced in 1982, when the first conferences for Afro-Caribbean and Asian senior citizens were held in Lambeth and Ealing respectively. SCEMSC aims to bring together information about service and other provision for the ethnic minority elderly population and to act as a resource and reference centre. With funding from the King's Fund Carers Unit, SCEMSC and Help the Aged have been drawing up a report on carers in three communities in Southwark, due for publication in 1989. Further information from Standing Conference of Ethnic Minority Senior Citizens, 5 Westminster Bridge Road, London SE1 7XW. Tel 01-928 0095.

- **Silly questions and good sense.** This article by C Cloke published in 1986 in *Geriatric Nursing* (**6**, 2: 10–13) gives an outline of what is involved in a local gerontology forum.

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Above titles available only as counter sales at King's Fund Centre, 126 Albert Street, London NW1 7NF. Tel: 01 267 6111

If you have difficulty obtaining any of the above titles please contact the Primary Health Care Group direct.

What do elderly people and those who care for them really want from community health services? This report suggests ways in which managers and professionals can make community care more responsive to elderly people.

Like everyone else, elderly people want information about what services are available; to have their health needs met promptly and in planned and predictable ways; to be consulted about their care and treated with respect by professionals.

Negative attitudes towards old age are so pervasive that we may not always recognise discrimination against elderly people. The report examines ageism and its effects in health care. It describes how elderly people from black and ethnic minority groups are affected by racism. Health professionals, argues author Jocelyn Cornwell, have a special responsibility to be aware of their prejudices and to challenge ageism and racism.

Part Two of the report is a resource for those who want to make changes. It includes many examples of good practice and sources of further information and help.

Jocelyn Cornwell is a locality manager in the Community and Continuing Care Unit in Islington Health Authority. Before entering general management in the NHS she was a research fellow in the Department of Health and Social Welfare at the Open University where she worked on a study of older people's beliefs about health and illness. She has a PhD from London University.

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