Looking Forward to Care in Old Age

Expectations of the next generation

Ros Levenson, Mercy Jeyasingham and Nikki Joule
Based on discussions with seven focus groups of people in their 50s, living in different communities in London, this paper reports on what kind and quality of care they want, and the type of housing, residential and community care options they expect. It also probes how roles within families and parents’ expectations of their children caring for them, are changing.
# Contents

**About the authors**

**Summary**

**Part one: Introduction**

**About the study**
- Background 5
- Using focus groups 5

**Methodology**
- Recruiting focus group members 7
- Groups held 7
- The seminar 7
- Analysing and reporting the material 7

**Part two: Findings**

**Access**
- Ageism and age discrimination 9
- Information, advice and advocacy 9
- Equity and eligibility 10
- Care management and assessment 11
- Paying for care 11
- Changing views on access 14

**Quality**
- Food 15
- Communication 15
- Choice 16
- Independence 17

**Housing and environment**
- Staying in London 18
- Staying at home 19
- Retirement communities 19
- When to move 20
- Sheltered housing 20
- Safety and security 22
- Equipment and aids 22
**Support in the community**
- Day care 23
- Home care 24
- Transport 25
- Social life and activity 25

**The role of children and families**
- What participants wanted from their children 28
- What participants expected would happen 29
- Changing roles 29
- Discussing future care 30
- Looking after one other 30

**Residential facilities**
- Independence and personal identity 31
- Standards of care and facilities 31
- Benefits of residential care 32
- Respite care 32

**Older people with dementia** 33

**Issues for black and minority ethnic older people** 34

**Changing expectations** 35

**Priorities and suggested improvements** 38

**Conclusions**
- Looking to the future 40

**References** 42

**Appendices**
1: Topic guide 43
2: Scenarios used in focus groups 44
3: Participant data 47
4: Choices and priorities exercise 49
About the authors

Ros Levenson is an independent researcher and policy consultant and a visiting fellow at the King’s Fund. She has published widely on a range of health and social care topics, and has a particular interest in older people and tackling age discrimination.

Mercy Jeyasingham is an independent consultant, researcher and trainer. She has a management background in the voluntary sector and social services and a particular interest in diversity issues.

Nikki Joule is an independent health policy consultant, researcher and writer. She has a particular interest in people with long-term conditions and user involvement in health and social services.

Acknowledgements

We would like to thank all those who participated in the focus groups and the seminar: Sarah Robinson at the King’s Fund for excellent administrative support; the East London Chinese Community Centre for hosting the first focus group, and particularly to Dorothy Ng for setting up the group and interpreting; Jo Moriarty for help with setting up the group at King’s College, London; Fiona Fisher for help in setting up the group from the Royal College of Nursing; Ruth Harris for help with setting up the group at Queen Mary and Westfield College; Elizabeth Bayliss and Social Action for Health for setting up the group held at the Brady Centre and Zaman Barbhuiyan for interpreting; Jazz Brown for help in setting up the Nubian Life (African-Caribbean) group; and Sue Newman at Brent Irish Advisory Service (BIAS) for helping to set up the Irish group.
About the study
In late summer 2004, the King's Fund commissioned a study, as part of its Care Services Inquiry, to look at what middle-aged people will require from care services that they might need in the future, as they grow older and find they are less able to look after themselves. The material for this study was collected through focus groups comprising people who were approximately in their 50s. We held seven focus groups in different parts of London. Between them, we aimed to achieve as varied a coverage as possible in terms of socio-economic and ethnic backgrounds of the participants. We also held a seminar after the focus groups were completed, to explore the issues further.

Findings
Access
A number of different aspects of access were raised and discussed in the groups. Participants saw ageism and age discrimination as impeding access to good-quality services for older people.

Access to information, advice and advocacy was a concern for all, but was particularly so for some people from black and minority ethnic communities, where there may be a need for translated materials or for information to be disseminated more appropriately.

Participants commended advocates for older people, though it was not entirely clear how they envisaged the role. They seemed to see it as a combination of giving information, speaking up for older people, and helping them access care.

Many people in the groups had some experience of trying to access care for parents and were exercised about the inequity of access to, and quality of, care across the country. Some felt that services were better outside London. There was a concern that eligibility criteria were applied inequitably and favoured some types of needs over others.

There was much discussion and concern about paying for care and how affordable it was. There was little agreement, however, about which services should be considered ‘essential’ and therefore provided with public money, and which might be considered optional extras and financed by individuals.

Quality
There was broad agreement, across the focus groups, on what types of principles would be at the heart of good services. They included:
dependability and reliability
continuity of care (individual or team-based)
adequate supervision of services
cleanliness (professionals should wash their hands)
well-trained staff who have higher status than they currently have, and are valued for what they do
staff not working beyond their competency
safe services, with proper background checks carried out on all people who come into the home to provide care and carry out other tasks
sensitivity to ethnicity-related needs
willingness to take carers' views on board
focus on individuals
positive staff attitudes.

In addition, participants identified food as an indicator of quality in services, and this was an issue that was very important to them – particularly to members of the Chinese and Irish groups.

Being able to communicate with those providing care services was important to all the groups, and was a particular issue for those who did not speak much English. For most, communication was not only about being able to give instructions, but was also related to being able to interact socially.

Participants identified choice and maintaining independence as essential aspects of good quality services that recognised people’s individuality. People expressed independence in different ways, and mentioned several kinds of choice:
- choosing to do (or not to do) things when it suits the individual
- having a choice in where to live
- being listened to about how one wants to dress
- choosing when and how to take risks.

Some participants wanted to think ahead about how they could make sure their current choices and preferences were implemented if they later became less able to make their views known. They pointed out that to facilitate choice, social care agencies need to take mental abilities into account and make regular assessments, but they also need to explain potential risks to the service users.

**Housing and environment**

Participants discussed whether London was a good place to grow old. There were differing views on this issue, and about whether it was desirable, or possible, to return ‘home’ if the person was not originally from the city.

There was agreement, however, that staying in one's own home was generally desirable. Some wanted to stay where they were whatever, although others were prepared to move house, or even area, to live in an optimum environment in terms of social networks and housing.
Participants explored the idea of retirement communities as a positive option, though some were not keen on living in communities consisting only of other older people. The timing of a move to such a community, or to sheltered housing, was discussed at length, and there was a suggestion that there should be ‘homes for life’, in which people could remain as their circumstances changed. The importance of space in sheltered housing was highlighted – not only so that people might have their possessions around them, but also so that they could receive visitors, and even have friends and relatives to stay.

Security was an important consideration in deciding how and where they would live in the future. They would require a range of measures such as alarm systems and wardens.

**Support in the community**

Participants recognised the need for care services to support them to live in their own homes, though the discussion about the kinds of support they might want was heavily influenced by their knowledge and vicarious experience of existing services.

People wanted a broader range of home care services than they thought was currently available – for example, they wanted help with domestic chores. They wanted services that would help them maintain their independence and their ability to exercise choice, such as having someone to take them shopping rather than doing the shopping for them. They also wanted care services to provide a social function.

Social interaction and activity were very important. There was enthusiasm for day services – mainly for the opportunities they provided to socialise, although people were not sure that they would enjoy some of the activities that are currently offered. Participants saw themselves engaged in a range of activities as they got older, including educational pursuits. Outings were important too, so transport was a key issue.

**The role of children and families**

One of the most striking and consistent findings from the focus groups was a broad agreement that one’s children would be unlikely to be one’s main or sole carers. Relatively few people wanted to receive a major part of their care in old age from their children or other younger members of their family. Most did not expect their children to be their main carers and, unlike them in relation their own parents, did not think that their children expected to care for them.

Participants generally felt that discussing future care plans and wishes with their children was too difficult.

**Residential facilities**

On the whole, participants strongly disliked the idea of residential care. This was usually because of a perceived loss of independence, and because of concern about the current quality and standards in residential care facilities. However, some saw positive aspects of residential care – mainly in terms of safety and for the companionship it could provide.
Older people with dementia
Participants in many of the groups were concerned about their future care needs if they developed dementia, and how their wishes might be accommodated in such a situation. The issue of managing risk was considered very important, and was seen as potentially compromising choice and autonomy, which were also considered very important.

Issues for black and minority ethnic older people
Most participants felt that access to, and needs for, services might vary across different minority ethnic groups. However, although they recognised specific needs, few believed that these should be met by providing separate care facilities but rather by enabling access to culturally specific facilities, such as Chinese supermarkets. Language remained an issue for some, and others talked about the need for an understanding of their culture and the importance of being around people from similar backgrounds.

Changing expectations
There was general agreement that this generation had higher expectations of old age than their parents. They had generally had better opportunities, more money and better health. Women, in particular, had a very different experience from that of their mothers’ generation. This generation were more likely to assert themselves and see care provision as a right they had earned.

Priorities and suggested improvements
Overwhelmingly, participants wished to have services that enabled them to maximise and retain their independence. They wished to be valued as individuals and have services that recognised their individual preferences. Many also stressed the value of low-level, preventative services, such as access to cleaning and maintenance services. Co-ordination of services was a key aspiration. They did not want to have to deal with different agencies and would prefer to have fewer, multi-skilled, staff delivering their various care services.

High on the priority list for many were concerns that are not conventionally seen as care services – for example, improved transport and access to leisure and educational opportunities and other support to facilitate social interaction.

Conclusion
There is some consensus among middle-aged people about what they will need when they are older. There is an aspiration that their individual preferences and needs will be accommodated within future care services and a very strong desire to remain in their own homes, supported by a range of services, including help with housework and maintenance.

A very strong message is that members of this generation do not expect, or want, their children to look after them when they are older, although there is a need for more discussion with families and friends about what they do want for themselves when they are older, and how to prepare for that.
About the study

Background

In late summer 2004, the King's Fund commissioned a study as part of its Care Services Inquiry to look at what middle-aged people will require from care services that they might need in the future, as they grow older and find they are less able to look after themselves. It would consider participants' preferences for:

- where care and support should be provided
- who should provide it
- how it should be provided, in order to maximise their quality of life.

The King’s Fund also wanted to know how the preferences of people who are currently middle-aged compared with those of their parents. The study aimed to explore what trade-offs people would be prepared to make should their future circumstances make it difficult or impossible to achieve their ideal preferred care solution.

Using focus groups

The King’s Fund envisaged that the material for this study would be collected through focus groups made up of people who were (approximately) in their 50s. (For more information about how the group members were recruited, see Methodology, p7.)

Focus groups are a tested method of social and market research. Powell and Single define a focus group as:

... a group of individuals selected and assembled by researchers to discuss and comment on, from personal experience, the topic that is the subject of the research.

(Powell and Single 1996)

In this project, we were not only asking people to draw on their own experiences and to discuss a very personal and sensitive topic; we were also asking them to infer what they might want when they reached an age and level of physical or mental frailty that they had not yet experienced. This is not an entirely new use of focus groups, but we were uncertain how the participants would respond to this challenge. We did not know whether they would want to be involved in such discussions, or how far they would feel able to imagine what they might want in the future. Moreover, we would be discussing scenarios in which they would need care, which most would rather not have to experience at all.
In practice, although recruiting group members was challenging, this was more a reflection of the tight schedule than the context of the discussions. In principle, there was no problem recruiting willing participants or encouraging them to think about the issues, but it was more difficult for people to identify ‘trade-offs’ and priorities than to consider broad principles.

**VIEWS ON FUTURE CARE NEEDS**

It was interesting to see how people formulated views on an issue of which they had only indirect personal knowledge at best, in the context of a two-hour focus group. Many people seemed to have already given the issues considerable thought. A minority had worked in or around health or social care, and a much larger number had been closely involved with care service issues (or expected that they soon would be), as they had relatives in need of these services.

Many people also seemed to have given considerable thought to what they would want for themselves – often in response to some knowledge of a poor-quality care service that they would not want. However, some aspects of care were more familiar than others to the majority of participants. For example, people could readily identify with the need for help with household chores – not least as some employed domestic help already. However, discussions on personal care were less detailed, since they found it harder to imagine themselves as recipients of this type of care. In this context, the groups tended to discuss general principles of good care (such as choice or continuity) rather than details.

We were able to mitigate this to some extent by introducing brief scenarios, either about fictitious individuals or based around care settings, to help people imagine unfamiliar situations. (For scenarios, see Appendix 2.)

In addition to drawing on personal or vicarious experiences of care services, people tended to want care services in their old age that evoked a time and place when they had felt secure and cared for earlier in their lives. So, their descriptions of ideal retirement communities sometimes conjured up a partly remembered and possibly idealised ‘golden age’. For example, one participant referred to:

> Having someone walking around the neighbourhood is important. That’s what the postman or milkman used to do.

Others fondly remembered the family doctor who knew everyone in the community and made domiciliary visits, and that was their ‘gold standard’ for good future care. Some remembered village life where people stayed well until they died peacefully of old age. To say that these remembered situations may be idealised does not mean they are irrelevant or inappropriate. Rather, it suggests that, when confronted with the unknown, it is easier to draw on the past than to think afresh about a totally new set of possibilities. As one participant said:

> You base your expectations on your own experience.

That being so, it is hardly surprising that people’s views tended to be formulated in support of, or in opposition to, existing services. Radical thinking about care services was relatively rare, although many people wanted significant quality improvements,
more choice, or other variations from what is routinely available at present. The big question is whether the aspirations and assertiveness of the baby-boomer generation will lead to piecemeal reform or to a radically different array of care services for the future.

**Methodology**

**Recruiting focus group members**

We set out to make the focus groups as varied as possible, in terms of socio-economic and ethnic background. We also aimed to hold groups for people in different parts of London. We employed a range of approaches, determined partly by time pressures. These included:

- **Cold calling to employers thought to have a significant number of middle-aged employees** This had limited success, in that the Royal College of Nursing was the only workplace to provide participants. Despite some goodwill in other firms and considerable effort on the part of the researchers, we were unable to set up any other work-based groups.

- **Following up direct and indirect contacts** This led to convening focus groups at the East London Chinese Community Centre (the Chinese group), Social Action for Health at the Brady Centre (the Bengali group), Nubian Life (the African-Caribbean group) and the group at Queen Mary and Westfield College. The group at King’s College, London, was arranged with the help of Jo Moriarty, a member of the Independent Committee for the King’s Fund Care Services Inquiry. In other cases we did not receive a positive response in the time available.

- **Approaching voluntary organisations with which we had no pre-existing contacts** This led to several unsuccessful attempts to convene groups and to one successful one (the Irish group).

In all approaches we were careful to stipulate the age group that we were seeking, and by and large we succeeded in this. However, two of the voluntary organisations that were initially willing to be involved were unable to recruit the right age group and, like several others, had assumed that participants could include older people who were currently receiving care. In fact, the age profile of the African-Caribbean group was higher than the target. However, those slightly older participants were able to make a useful contribution.

**Groups held**

We held discussions with the following focus groups:

- East London Chinese Community Centre group (15 people)
- African-Caribbean group, Nubian Life Centre, west London (9 people)
- King’s College group, south London (17 people)
- Royal College of Nursing group, central London (8 people)
- Bengali group, Social Action for Health, east London (7 people)
- Irish group in Brent, north-west London (3 people)
- Queen Mary and Westfield group, east London (5 people).
**The seminar**
In addition, following all the focus groups, we held a seminar in central London at the King's Fund, to which we invited the focus group participants, interested individuals, and people from trade unions and key organisations. In total, 41 people attended.

**Analysing and reporting the material**
Where possible, we have used participants’ own words in this paper, but in the case of the Chinese and Bengali groups, we were dependent on interpreters.
Access
Participants raised concerns about the problems that they thought older people might have, and that they themselves might experience, in accessing care services.

Ageism and age discrimination
Participants saw attitudes to old age and to older people as crucially underpinning older people’s access to care services. They felt that ageism was common, and several had already experienced its impact:

- You can get dismissed, for example, by younger people, or even by people your own age, saying ‘It’s your age’.
- I saw the optician about my eyes and I said I could not see out of my left eye. He said it was my age. But I said to him, ‘My right eye is the same age as my left eye!’.
- My mother wants to go to do a bit of physio, but her gym doesn’t want older people.

Participants across the groups felt that it would help if perceptions of old age and disability were more positive. There was also a consensus about the need to think about older people as individuals, and not to have rigid attitudes based on chronological age. Participants at the seminar expressed concern about the lack of respect for and value of older people, and the need for legislative protection. A participant who had lived in the United States said that people who did have this protection were more likely to stay in work.

Information, advice and advocacy
Another important discussion about impediments to access centred around a cluster of concerns about information, advice and advocacy. All groups found access to these problematic, but the most extreme comment was from a Bengali participant, who said:

- I don’t have any idea what help I can get.

Participants in the Bengali group wanted to be able to access advice on care services and other issues from somewhere they saw as friendly, convenient, and easily accessible. They wanted somewhere that offered refreshments where they could feel at ease and share their experiences with others, such as the community centre in which the focus group took place – a well-known local resource.

The participants felt that advice and information needed to be tailored to the needs of specific groups. For example, members of the Irish group highlighted the difficulties in
accessing information experienced by travellers – those who were settled and those who were travelling alike. They pointed out that, while a one-stop shop might be useful, various other solutions might need to be explored as this group of people often had low levels of literacy.

Group members felt that lack of information could prevent people from accessing services that were available. For example, one member of the King’s College group said that although some day hospitals provided exercise sessions, people did not always know how to ‘get into the system’.

Members of two focus groups commended advocates for older people, though it was not entirely clear how they envisaged the role. They seemed to envisage an independent person, speaking up for them and helping them to access co-ordinated care.

**Equity and eligibility**

Even where information was available, participants did not see this as a guarantee of access to good care services. Inevitably, they tended to draw on their experiences of older relatives in trying to gain access to care services.

First, they wished to see a system that was apparently more equitable across the whole country. Those with experience of care services outside London felt that London lagged behind other places:

> Up north, where my mother is – she’s 89 – there was automatically a lot of help. It is different in different parts of the country. It is a postcode lottery, in terms of facilities and treatments. And the policy of having to pay for social services not nursing services needs to be sorted out so it’s the same across the whole country.

Second, they felt that eligibility criteria favoured some types of need while excluding others:

> When my father was terminally ill, we had every piece of care we could want. When he died, all the help for my mother suddenly stopped. A lot depends on whether your GP will agree to an assessment by a social worker. And social workers are over-burdened anyway. The whole thing can fall apart. You get services if you are terminal.

A member of one group reported that her 91-year-old mother had been assessed as ineligible for respite care, although the local authority could send carers to get her up and put her to bed instead. The participant felt that this solution was unsatisfactory because it would not ensure her mother’s safety between visits. Members of the same group felt that in order to prevent deterioration, it was important to get care when it was needed and not ‘six months down the line’. They wanted a less bureaucratic system, with fewer people involved in making assessments that seemed pointless and repetitive.
Similarly, a person in the Royal College of Nursing group wanted services to be more immediately responsive so that the patient did not have to wait 'weeks for help, or hours on the phone'. Others mentioned the frustration of trying to reach inaccessible services, including some that have no telephone answering machines.

Several participants reported that they did not wish to have to fight for services, as their relatives had to do:

>You have to fight for everything. My mother had a heart bypass and the nurse said she wasn’t entitled to a carer. I had to insist. But if you’ve got nobody…. My generation has got children at one end and elderly parents at the other!

**Care management and assessment**

Participants had various views on how assessment could be improved, to improve access to suitable care services. The preference was for one person to be responsible for an assessment, and for this person to be ‘independent’ of social services. One participant described this role as an advocate or key worker, whose job it would be ‘to control everything for the client’.

In one group, there was some discussion about the need for assessments to be ‘continuous’ and to take account of changing needs. A disabled participant said:

> I am worried that I will be more disabled then than I am now and will have to rely on others – for example, if I am forgetful or not so able to communicate my needs. Someone needs to foresee my needs and maintain my safety.

**Paying for care**

All the groups had many concerns and views about the affordability of care, which was seen as a key aspect of access to these services. The group discussions were taking place around the time that the future affordability and adequacy of retirement pensions was making headline news. This may have made people particularly aware of the issues:

> The big problem is finances. If you are active for 30 years after retirement, how will you finance that?

> The cost – free or means tested? Cost can be quite important. There are hoops to jump through for means tests and a free service would be good, as we have paid in. And we may have to work until we are in our 70s! They keep changing the goal posts with pensions.

Affordability of services was a particular issue for some members of the African-Caribbean group, who were among the oldest of the participants. They were concerned about not having enough money to pay for care and about the high cost of other financial commitments, such as council tax.

In other groups, some participants pointed out that affordability and choice and control were linked:
For my mother, it was important it was someone she trusted. She was able to stay in her own home and she had someone she could trust, and she could negotiate. She was in a position to pay. But it is not always easy to find someone, even if you can pay.

**EXPECTATIONS OF THE STATE**

Some were very cynical about what the state might provide:

*The government has realised that it is cost-effective to let people look after themselves and provide minimal services. This can place a high burden on carers. Care should be focused on the person and their needs.*

*The problem with funding through taxation is that I wouldn’t trust the government to pay for my care.*

By contrast, others were fairly enthusiastic taxpayers:

*If we pay low taxes and don’t have a good pension, how can we expect future taxpayers to pay for us? I want to pay for my care. I’ve got a pension. I save very regularly.*

*Better to pay more now so costs are spaced out over the years.*

There was a lot of discussion – and little consensus – about what people expected to pay for themselves and what they thought it reasonable to expect to be funded from the public purse. It was easy to get agreement on broad statements about the state being responsible for basics, and individuals responsible for ‘luxuries’, but on the whole, people found it hard to grapple with exactly what might underlie these generalisations, and comments like the following were not uncommon:

*Government should pay for anything that enables you to function.*

Several participants made the point that they expected the government to pay for their care, as they were paying high taxes. This point seemed to be particularly strongly felt among people who had come to this country from other countries (such as some members of the Chinese group) where taxation – and public services – operated at a lower level. They felt that as they had adapted to a society where taxation was high, the benefits in old age should be commensurately higher too. A member of another group observed:

*I would like a scooter and a surgical corset. I am trying to help myself, so the government should pay. I paid through income tax when I worked.*

At least some participants felt that the following services should be provided out of the public purse:

- cleaning
- basic levels of help in the house
- accident prevention at home
- rent
- medical care
- all daily expenses, including food
- annual complete medical check up, not only for those who are ill
- transport.
However, many felt that it was reasonable for them to contribute to, or pay for, such things as:
- day-to-day household living expenses, including food
- massage
- pedicures, as opposed to chiropody
- leisure activities
- hairdressing and make-up
- outings (though these should be subsidised, if possible)
- luxuries.

On some items, such as gardening, there were differing opinions. Some saw gardening as a ‘luxury’, while others considered it vital.

> Probably you should pay towards gardening, but for some the garden might be the most important thing – when the garden goes, it is an indicator and reminder of failing health.

Similarly, some saw home maintenance as integral to effective care services, but others did not.

**PASSING MONEY ON TO FUTURE GENERATIONS**

There was considerable disagreement about how far charges should safeguard people’s ability to pass on any wealth to the next generation:

> Yes, you could have an upper limit of the size of property to be maintained. But the rest of the money – you should be able to leave it to your family, or use it as you want.

> I have always paid for health care and have taken nothing back – for example, I paid for my children’s university education. So when I get old, I don’t expect to have to pay.

> I feel the mark of a civilised society is how we care for others. I come from a mining family and never had anything. My parents died young and never earned much. Every section of society should get the care they are entitled to as humans – for example, dignity and choice.

> Extremely wealthy people should pay.

One participant said that it was more important to have a comfortable life than to leave money to one’s children. She added:

> There shouldn’t be an expectation that people can hold on to their homes at the taxpayer’s expense, though you should be able to release some of the equity on your home to help.

There was one suggestion that the ability to pay may be a one-generation phenomenon:

> We will be more fortunate than those following us – if the younger generation can’t get on the property ladder. We have equity in the house that we can draw on.
CONTRIBUTING TO THE COST OF CARE

Some of the greatest willingness to pay was expressed by Bengali men, although it was evident from what they said that they were all on very low incomes. Nevertheless, they expected, and even wished, to make a contribution – particularly for personal care.

The Bengali group explained that often their children provided some of their care, and that they wanted to give their personal carers some money to show appreciation of what they do. They explained that in Islam one should show respect and love in order to receive respect and love and that giving care and showing appreciation of it was part of this.

One participant in another group emphasised the importance of services reflecting the priorities of the individual client, even if they are provided by the state:

\[
\text{If I need a home help, that should be paid for and the home help should do what is important to me to have done. For instance, I might not care if the net curtains are not washed, but I don’t want bits on the carpet.}
\]

Some participants expressed concern that older people may begin to pay for services from their own resources – for example, for a high standard of residential care – but they may then find that the council is unwilling to sustain that level of care when the person’s own resources run out. Others resented the procedures for financial assessment:

\[
\text{They have to find out so much before they give you anything – papers and forms about how much you are getting, and how much savings. They try to find out if you’re worth it.}
\]

DIRECT PAYMENTS

Some people liked the idea of direct payments as they felt this would give people better access to services. The idea was particularly attractive to members of the Bengali group, one of whom said:

\[
\text{With direct payments, you choose who is to help you, so language would not be a difficulty.}
\]

A member of the King’s College group said that carers and older people should have some support in recruiting care staff. She felt that within the current system, it was not easy to help people find support services that were trustworthy.

Changing views on access

It was difficult to assess to what extent the expectations of middle-aged people now differ from those of the previous generation in terms of accessing services. Those who grew up outside the UK acknowledged that because their whole way of life is different to that of their parents, their expectation of their future needs and access to services is very different. However, in one brief discussion about fighting for right of access to care services, one person declared:

\[
\text{We need a grey panther movement.}
\]
Quality

Across the focus groups, participants tended to agree on the types of principle that would be at the heart of ‘good’ care services. These were broadly comparable to what older people themselves have said about quality in care services (Levenson and Joule 2004).

The general aspects of quality that people wanted were:
- dependability and reliability
- continuity of care (individual or team-based)
- adequate supervision of services
- cleanliness (professionals should wash their hands)
- well-trained staff who have higher status than they currently have, and are valued for what they do
- staff not working beyond their competency
- safe services, with proper background checks carried out on all people who come into the home to provide care and carry out other tasks
- sensitivity to ethnicity-related needs
- willingness to take carers’ views on board
- focus on individuals
- positive staff attitudes.

Continuity is important – for example, having the same carers. Older people need to have the same support so that they build up confidence. For example, the same person should put them to bed.

We would want to be recognised as more than someone who you just feed, water and dress. There is much more to care than this. Care staff should put themselves in the place of the older person and should take time to find out about the person and know their individual preferences. Inspection doesn’t check this sort of thing.

In addition, several groups indicated that they did not draw much distinction between health care, on the one hand, and social care and support on the other. They rated highly access to a GP as an aspect of care, and considered that having someone to accompany them to a GP and offer ‘moral support’ was an important aspect of care – particularly for those who might have problems with their vision or hearing.

Food

Members of all groups considered food to be important to the quality of their lives, and saw good food, appropriate to individual and cultural preferences, as an important dimension of ‘quality’. Members of the Irish and Chinese focus groups felt particularly strongly about this.

The Chinese group unanimously and enthusiastically rated good (Chinese) food as their highest priority, alongside opportunities for a good social life, companionship and personal care. The prioritisation of food influenced their requirement in terms of support to stay at home, since access to someone who could shop at Chinese supermarkets, or take them shopping, was very important. It also made the need for transport to suitable food shops important, and this was a factor in where (as well as how) they might choose to live.
The Irish focus group was also concerned about having good, appropriate food as they grew older, especially if they could no longer prepare it for themselves. They felt strongly that Irish people’s food preferences were not appreciated in England, as they were assumed to be similar to English preferences. In fact, they said, Irish people often find meals services inadequate as they tend not to include the quantity of potatoes, cabbage and plain food that many Irish people enjoy:

Food is very important: bacon and cabbage and potatoes and bread, all important – especially potatoes, and the quantity of them.

Even when people have lived in England for years, they still want Irish-style food.

A glass of stout at night is important too for some. This is not seen as boozing, but good for you – medicinal.

They also emphasised that in Irish culture, social life often centres around food and hospitality:

We didn’t skimp on food – there was always some to spare, an extra portion in the pot in case someone dropped round. It is important to be able to offer food to friends and neighbours.

Among all the participants at the seminar, ‘regularly eating your preferred food’ was the most frequently prioritised service option.

**Communication**

All the groups discussed communication issues, and rated effective communication as an important aspect of dealing with care services. Drawing on their experience as a visitor, one person described a care home where staff appeared to be poorly trained and largely comprised agency workers who did not speak English very well.

Language was also an issue for participants whose first language was not English, who were very concerned that whoever provided their care services should be able to communicate with them.

One Chinese participant identified their greatest need as likely to be:

Home help – but must be able to communicate in Cantonese.

Another member of the same group thought that an emergency alarm system would be helpful but again, that the person answering it would need to be Chinese speaking.

Several people in the Chinese group identified ‘company’ as an essential component of care services, and felt that the people providing this company had to be able to communicate in their own language.

One of the Bengali men anticipated particular problems for his wife in the future, as their daughter had married and left home. His wife does not speak English and requires interpreting help.
Even for those who do speak English, good communication is no less important. One of the Irish participants observed:

*It is important how staff approach clients.*

**Choice**

Participants identified choice as an essential aspect of good quality care services. They saw it as a means of recognising individuality and maintaining dignity:

*Choice is very important – older people must be given a choice and not told where to go.*

Participants wanted choice in:
- what time and whether to do things
- where to live
- how to dress – not only ensuring that people have their own personal clothing in all care settings, but taking into account additional preferences
- when and how to take risks.

The issue of risk-taking was important to many people, although there was a spectrum of opinion about whether, and when, they thought it reasonable for people to curtail their freedom and choice to protect them from possible harm:

*I would hope that people would leave me alone to take risks for myself. It’s only when I become a danger to myself that society has the right to intervene.*

*I want to be seen as someone who can make my own judgements – If I want to stay in my own home and take my own risks, I would like to be able to do that.*

*If I am a risk to other people, then that is different – others would have to intervene. If my dignity was impaired – for example, if I was going out in my nightie in the street – then again, that is something else, and I would want people to intervene.*

Some people wanted to think ahead about how they could ensure that their current choices and preferences were implemented if they later became less able to make their views known:

*I’d want to die. I’m quite positive about that. I’ve discussed it with my friends. I feel there is no point in my living if I don’t have a worthwhile life.*

*‘Informed choice’ is a key phrase. You need to understand what might happen. This is why one might consider a living will or advance directive.*

Participants suggested that risks were inherent in any situation – not just in someone’s own home.

*It’s about managing risk. You can be at risk wherever you are. But a key worker needs to assess risk and suggest ways of reducing it. There are also risks in taking someone to live in a care home. Your level of confusion increases when you are taken out of your home environment – so it gets worse.*
People pointed out that facilitating choice involves taking mental abilities into account, and regular assessments are necessary. However, the way in which potential risks and pitfalls are explained to patients is also important.

**Independence**

Closely linked to the concept of choice is independence. Most groups saw this as an important issue, although members of the Chinese group appeared to have a greater sense of group identity than the others. For some participants, particularly in the Chinese group, while independence was seen as desirable, other things such as social life and interaction with other people were considered equally important.

The concept of remaining independent while still receiving help from care services varied from person to person. A member of the King’s College group said that they would want someone to take them shopping rather than actually doing their shopping for them. Others, such as some members of the Chinese group, wanted group transport to the supermarket so they could be as independent as possible once they were no longer mobile on their own.

In contrast, another participant, from the King’s College group, expressed the view that once one needs help:

*Independence is an illusion – you are not independent.*
Housing and environment

Housing and environment were very important to all the people involved in the focus group discussions and at the seminar.

Staying in London

Three of the focus groups considered whether London was a good place to grow old. Participants saw the capital as having positive and negative characteristics. They saw general amenities and opportunities for leisure as being very good:

The amount of facilities for older people in London is actually good – libraries are open long hours, and so on.

But the quality of life is affected by factors such as patterns of migration. One Irish participant described the experience of the Irish community:

London is probably lonely for an old person – their family often not here – they are often all over the world now.

A participant from another group added:

It depends on where you live. A lot of friendship clubs are closing down, especially in inner London.

Participants who had experience of relatives accessing services outside of London saw care services – and particularly health services – outside London as being better than those in the capital.

I won't be living in London. Healthcare provision in London is appalling. We need to work out where to live now.

I don't imagine ending my days in London. Access to health services is so much better, for example, in Devon.

Members of one group said that many Irish people think about going ‘home’ – although that may be to an Irish community somewhere such as Liverpool rather than actually to Ireland. However, they said that this may not always be realistic:

Most people want to move out, but financially they can't actually do it, and also they don't want to leave the support network they have built up. They may want to go back to Ireland, but don't have the means.

Another participant pointed out that even if people do leave the capital, the transition is not always easy:

Sometimes people retire to places where they know no one. Social services are expected to put in place what people have lost.

One participant at the seminar talked about the loss of social cohesion as society becomes more affluent, and said that there was a need to explore ways of facilitating social cohesion in London. Another talked about how the built environment can have a
disproportionately adverse affect on the quality of life of older people and their ability to get out and about. For instance, major roads in some parts of London cut older people off from their friends and neighbours, and the preoccupation with security can impact on sociability.

**Staying at home**

Across all the groups, there was complete agreement that it was desirable to stay in one’s own home for as long as possible. However, for this to be possible, housing and environmental conditions had to be suitable. It also became evident that ‘staying in one’s own home’ meant different things to different people.

Some were emphatic that they wished to stay at home whatever happened, and not just ‘as long as possible’. Others wanted to live alone or in a small family unit, or with a companion of their choice, but were prepared to move house, or even area, in order to do so. Some were more attached to their current home, and gave greater priority to retaining it and remaining in a familiar community.

*I’d be happy with my friends. I’m active in my community and everyone keeps an eye on everyone else.*

*I’d like to stay in my own home. I’m involved in my community – they are all ageing, so it would be fun before the ‘drop-off point’!*  

Most people agreed that whether one stayed at home or not depended on one’s physical and mental condition. If they became unable to maintain their home and garden, they might choose a place that does not need so much maintenance. Participants saw upkeep and maintenance as particular problems for women.

*It might mean moving into more suitable accommodation. I’m good at DIY but it might be too much – you want a place that doesn’t need doing.*

*There is some personal responsibility. I want to be at home till I die, but it won’t be the same home as now, as it is far too big and away from the town. I want to be within walking distance of facilities, so I will downsize. You can’t expect maintenance of a seven-bedroom house in the sticks. You have to plan for different incidents, so I will take steps.*

*I want to live somewhere with a more normal community. We’re more willing to downsize than our parents were.*

Discussion across the groups acknowledged that people’s level of freedom of choice in housing reflected their level of income and type of housing tenure. Owner-occupiers might choose to move or convert their premises, and might well choose to downsize. Council or housing association tenants might be able to swap; some feared that there would be pressure to move out of council housing designed for larger families.

**Retirement communities**

The groups had some discussion of ‘retirement communities’. There were some perceived benefits. For example, participants felt that retirement communities could provide housing
and care for older people with different levels of frailty, so that people would not have to move away from friends if they needed additional care. Some saw the idea of a community with independent housing, supported housing and residential facilities as attractive. They spoke of retirement communities as pleasant and rather ideal village-type communities where everyone looked out for each other, as people were reputed to have done in the past.

Other participants had reservations about the idea of retirement communities, and felt that they could isolate the older people from the rest of the community. One participant’s father had moved to a retirement community, which had been fine when he was 60, but as his neighbours grew older and developed more health problems, things changed:

The only social event going on was funerals. I think elderly villages are a big mistake. This community was like being buried alive. The ideal would be to stay in a mixed community.

Some did not particularly care for the idea of retirement communities but felt that they might be necessary:

You need a mixed community, but there still comes a point at which you need help.

**When to move**

The question of when to move was a difficult one:

When you get older your friends die, so you need to build up new friends in your new environment. So the sooner you move, the better.

My mother is 90 and lives in a large house. It would kill her off if she had to move. I've persuaded her to have cleaning; perhaps gardening. I'd explore the possibility of live-in help.

The groups also discussed the concept of a ‘home for life’, with an emphasis on design that would enable people to remain in their home even if their mobility altered over time.

Moving is traumatic, especially when you get older. Homes should be built that are adaptable and allow people to stay in the same place.

**Sheltered housing**

Most participants saw sheltered or supported housing – either free-standing or as part of a continuum of housing and care facilities – as an acceptable option if someone needed care. They also saw it as potentially available to people who owned property as well as to those who rented.

Not everyone considered it vital for the sheltered accommodation to be in the immediate vicinity of family and friends. However, participants did feel that their sheltered housing would have to have good transport links, to enable visits to and from family and friends. If transport were available, one participant commented that distance would not be a problem:
It could be positive to be at a distance from family, but I would need to consider whether it would be stressful for them to visit – I don’t want to be a burden.

In contrast, members of the African-Caribbean group were clear that they would wish to stay living near family and friends, and that other benefits could not compensate for that.

Half the Chinese participants did not mind much about whether sheltered housing was close to where they currently lived. However, they felt it would be extremely important for some of their fellow tenants or residents to be of their own ethnic group, so that they could chat in their own language and watch the same television channels. They also mentioned that they were afraid of racial discrimination, so being together would offer support as well as companionship.

One participant, from another group, expressed a need for:

... more in the middle end between housing associations at one end and nursing homes at the other end: communities to live in – mixed age groups.

As with other types of move, timing was important:

If you leave it too late, you don’t have the energy.

There comes to a point when you can’t stay in your own home – you need that safety. You need both independence and a community.

To most participants, the principle of moving and receiving some support was not unthinkable, but a major concern was that they would not have enough space – either indoor or outdoor.

Sheltered accommodation is limited if you are used to living in a house with a garden. The loss of space is very important.

There needs to be creativity and flexibility in the design of places. For example, a couple could have two units.

Space was seen as important in enabling people not just to retain their possessions but also to be able to offer guests a spare room, and to have grandchildren and other younger relatives to stay. Guest suites are available within some sheltered housing complexes, but participants did not see these as sufficiently homely and personal to meet their requirements.

I would want to have spare room to have people to stay – not just down a corridor like in some sheltered housing – but actually as part of your home.

Other factors that participants considered desirable in sheltered accommodation included:

- keep fit classes and exercise
- good security
- holidays and outings
- the possibility of making new friends
- being among people with whom one felt a cultural affinity
- being able to take one’s own furniture and possessions.
One participant felt that resistance to moving away from totally independent living might be bound up with a wider resistance to change. She suggested:

> When you are used to living on your own for many years (for example, if divorced or bereaved young), you form habits being on your own, and it’s hard to imagine living with others.... It can be hard to break the habit. Isolation, though, is horrible.

> We should try and find a more communal way of living for people over 50, so they can prepare for their older years. Women often find that they are alone in their 50s ... but would not want to be identified as in need of older people’s accommodation. There needs to be something for this group

Participants saw moving into sheltered housing as a very big step, which, even in the best of circumstances, was a loss of independence. So they suggested having a trial period of a month or so, whether one was buying or renting sheltered accommodation – although they recognised that it would be more difficult to arrange this if someone was intending to buy.

**Safety and security**

In all the groups, people wanted to feel safe and secure in their old age. They felt that older people could be vulnerable – for example, to people masquerading as ‘the person from the water board’. As a result, they felt they would want a range of measures in and around their accommodation to maximise their security. For some, this would be an efficient alarm system. Others mentioned a working telephone and computer. One person recommended a ‘community warden’:

> My mum belongs to a club with a community warden. If people don’t turn up, the warden rings or visits to find out if they are OK. This service could be offered from the surgery.

Members of two groups felt they might benefit from remote surveillance using advanced technology, although they did not see it as an acceptable substitute for personal contact. Others were aware of emergency call alarms, worn on the person, but several were doubtful of how effective they were, as people they knew tended not to wear them, or found that they could not reach them when they actually needed them.

**Equipment and aids**

There was a limited amount of discussion about the aids and adaptations that people might want as they grew older. However, one participant was already concerned about this issue:

> My bedroom is downstairs and my kitchen is upstairs, so going up and down stairs is a problem.

In some of the groups, there was a sense of optimism:

> There’s a growth in gadgets that can be used, which can make a huge difference.

This was tempered by doubts about whether older people would actually use the gadgets, although one person very much wanted to do so:

> Technology to enable people to stay home is very important: I’d like a robot, please!
Support in the community

Wherever they would be living, and whatever the nature of their housing, participants generally agreed that they wanted support to help them live as full lives as possible in their communities. Discussion about which forms that support might take was heavily influenced by people’s knowledge and experience of existing services.

Day care

Generally, participants were positive about the idea of some organised day activities, although they were not always confident that the activities available were what they would want. This may have depended on the facilities that they had seen:

- My mother was compos mentis to the end. What she needed most was mental stimulation – that’s what I’d want. She went to the day centre three times a week.
- I would like something a bit more stimulating than traditional day care – maybe more educational.
- My mother went to a club, and at every coffee morning they paid a pound and they used that money to go out for the day. It was something to look forward to.

The Chinese focus group was made up of people who already regularly attended a local community centre, so it was not surprising that they were extremely enthusiastic about appropriate day care and day activities. Their list of requirements included ‘more day centres to enjoy singing and activities’ and ‘a Chinese elderly day centre providing a Chinese cook and workers’.

One group was given a scenario about a hypothetical day centre where the staff were very friendly and the lunch was good, but the person attending did not immediately feel that they had much in common with the other users of the centre. The participants had a variety of reactions to the situation:

- I’d continue to go. You can’t always make a judgement about what the people are like. And if you have enjoyed your lunch, at least you don’t have to do all that for yourself.
- I’d form a committee and change the day centre.
- I’d find another day centre!
- If you have got a friend, you can get them to come with you.
- Some social contact is important in itself. And routine is important in my life.

There was also some discussion about the need for day care activities to be part of a continuum of options, so that as people’s needs changed and the need for care possibly increased, they could move seamlessly into different kinds of care services. One participant described the situation of an acquaintance who went to day care in a residential home where they took part in activities:

They got to know the staff, so the transition was better.
Participants also showed some enthusiasm for integrating day services for older people with other, mainstream, facilities for all age groups:

*If the centre was on an adult education site, you could also access other activities.*

**Home care**

Participants’ experiences of, and aspirations for, home care closely reflected the priorities of older people as reported in recent literature (Levenson and Joule 2004). Across the groups, people wanted home care with the following characteristics:

- a reliable key worker
- a worker coming in at set times that are convenient for the client
- more centralised records, and individuals to keep their own notes
- adequately staffed services (as they perceived them to be currently understaffed)
- positive attitudes among staff.

*I might accept someone to give me breakfast – at a set time though. With social services, they’ve got so many commitments.*

*I would pay for someone to stay over – to help me go to the toilet.*

*I want practical, unselfish and ungrudging help.*

Their expectations of getting a good service were not high, based on what they had seen so far:

*I know someone whose stair lift was broken and she was stuck upstairs for three days, with nothing to eat and only able to drink from the bath.*

What participants wanted for the future was a much broader definition of ‘home care’. In particular, they seemed to find it easier to imagine needing help with domestic chores than with personal care and bodily functions. Those who did consider personal care were particularly concerned with being able to choose frequency and times of bathing.

While many recognised personal care as essential, participants were equally concerned about getting help with a range of other things that would enable them to remain in their own homes but living as independently as possible. Many wanted this support to entail more than the occasional speedy visit to deliver the shopping. One woman who had diabetes and already needed help predicted that further down the line she would need home care. However, rather than having the shopping done for her, she would want someone to accompany her to the shops, so that she could choose it for herself.

Participants came up with a range of considerations:

*Practical things are important: is your home up to standard and maintained? For example, getting taps fixed, and adequate heating (and being able to afford to switch it on), and having your laundry done, your hair washed, and toenails cut.*

*Changing curtains – who does this? My mother would do it herself and would maybe have an accident.*

*You would need someone to cook and clean the house.*
Some of the worst problems I had were not with finding a personal carer, but with finding a gardener. My mother’s considered moving so that she doesn’t have a garden.

**PERSONAL PRIORITIES ABOUT CLEANING**
The participants’ priorities in terms of home care varied greatly. Some worried about dust, while others were concerned about the state of the curtains. Some felt that the importance of cleanliness would depend on how much time a person spent at home: someone who was virtually housebound may be much more concerned about their domestic surroundings than someone who spent some of their time elsewhere. Having someone to do the basic dusting and hoovering was the seminar participants’ fourth-highest priority.

**SOCIAL CONTACT**
For some, the distinction made between help with practical tasks and the wish to have some company was blurred. These participants tended to view good home care as encompassing both. One participant thought that someone in this situation might want:

...a system like social services to pop in regularly and ask her if she is all right.

Another said:

*People can come and do things for you – for example, wash and dress, but this would not be mentally stimulating.*

Members of the Chinese group particularly stressed the importance of help that addressed social as well as practical problems. Another suggestion, from a member of the Queen Mary and Westfield group, was to have ‘a companion, like in Victorian times – a good idea, but expensive’.

Other participants added that care service employers need to ensure care staff are able to fulfil a social role as well as their other tasks:

*The psychological aspect of care is ignored completely. They need to be able to relate to the culture of the person, building up a relationship of trust.*

*It’s important that people coming in should be trained so they don’t spend their time off-loading problems on to the person they are caring for.*

**Transport**
Accessible transport was widely viewed as an essential element of supporting people in the community. Participants were often worried about how they would manage if physical disability, visual impairment or lack of money meant that they could no longer drive their own car. Among other things, participants wanted an electric mobility vehicle and another wanted dial-a-ride and free bus passes.

**Social life and activity**
Participants did not see the services that they required as fitting into the two distinct categories of practical help and social support, as defined by providers. They felt that as
social life and meaningful activity were explicitly linked to good health, they were therefore part of the remit of care services.

Instead of giving up, you need a challenge when you’re starting to go down. My mother had her garden as a catalyst.

Participants saw themselves spending their days in a variety of ways when they were older. Often they were at pains to refute the stereotypes:

Well, I don’t knit or play bingo.

Participants emphasised that they wanted to have a choice of activities to reflect the interests that they had always had, and possibly to enable them to develop new ones. Some looked forward to old age as a time to develop new interests and skills, and a time of opportunity for leisure:

In some ways, I see myself with more freedom when I’m older, and I’m looking forward to it.

I like to be around people – I need people. I have a study for reading and writing. I like to visit the country and write short stories about it. I am going back to music from when I was young. I’ve learnt embroidery – both machine and hand – and I design and make garments. I also like travelling.

It depends on health. I would like to do painting, develop IT skills, dancing… I would like to do these things but I can’t afford to do them now.

I would want to be able to have fun and then go back into my own space. Also spending time with my children and grandchildren, and going on holidays.

I am very ambitious: gardening – lots of beautiful flowers in the garden – and learning to fly a plane!

Others had considered the possibility of having to adapt their leisure pursuits as their physical abilities altered:

Music would be important if I weren’t able to do other things.

Most people regarded contact with others as important, and they wanted support in maintaining this in a variety of ways:

I like the idea of having people you know, in your home, to talk to.

I would like some activities for older people and some for mixed age groups.

Participants considered outings as being very important too. A member of the African-Caribbean group described the activities offered by their community centre:

I go to different clubs. We go to different places – last week, we went to Dalston market. They also go to the seaside and provide lunch.

A member of the Chinese community centre added:

I would love to see more assistance to centres like ours to have day trips every one or two months. Life can be very routine.
Many people said that they wanted to put something back into the community, and to be valued as they grew older. Some wanted to offer their skills and time to children and young people:

*I want to give something back as well as take. I could help kids read at school.*

In order to achieve some of these things, participants suggested a role for public authorities and voluntary schemes, in community development and starting up befriending schemes:

*I think there should be more money put into creating communities. I think there are people who would do this. My mother-in-law volunteers for a transport scheme. Our generation will perhaps be able to do this once they retire. We need an organiser or co-ordinator – it used to be churches in the past. We need to re-create that – have local lads doing the gardening.*

Some people in the Chinese group highlighted their particular needs in achieving a good social life:

*There are language limitations. So, by the time someone has retired, their social circle would be more restricted. So we’d want trips, maybe twice a year, to places that we don’t normally go. It would enrich our lives and reduce isolation from society.*

*I sit behind the checkout in the supermarket while my wife shops, as my legs aren’t very good, and the old ladies chat to me. I’d love to learn more English to chat to the old ladies. And I would like to continue to cook, to enjoy food and family life.*

Some participants – particularly members of the Chinese group – saw links between social life and exercise. They wanted a companion to go for walks in the park, and some of them enjoyed activities such as table tennis.

Several people emphasised the importance of mental stimulation and the harmful consequences of being denied it. People wanted to learn new skills and to attend classes run by schemes such as the University of the Third Age. Some wanted to do a degree. Several people saw access to the internet as another way of maintaining social contact.

At the seminar, access to the internet and up-to-date IT equipment were among the most frequent extra options that participants required.

Some wanted the opportunity to work beyond retirement age, possibly in a more flexible or part-time manner, while others were eager to retire, if their financial situation permitted it. Some feared that they might have to work into extreme old age, whether they wanted to or not, purely to make ends meet. Some feared that ageism in the workplace would prevent them from finding work.

Finally, several people looked forward to an old age as a ‘grey panther’, attending demonstrations and writing angry protest letters.
The role of children and families

One of the most striking and consistent findings from the focus groups was a broad agreement that one’s children would be unlikely to be one’s main or sole carers. Discussion on these issues was around a variety of questions:

- What did participants want of their children, in relation to their own possible care?
- What did they expect of their children?
- How did this vary, if at all, from their own role in relation to caring for their parents, or from the experience of previous generations?
- Had they discussed issues about their future care with their children?

What participants wanted from their children

Relatively few people wanted their own children or other younger members of their family to provide a major part of their care in old age. Some expressed strongly their desire not to have their children caring for them. Often, this was out of concern for their children’s well-being, but sometimes it was also a matter of their own preference:

*The overwhelming thing is I would not want my children to have to look after me. I don’t want to see younger people spending their lives looking after older people – they may have to spend many years doing this and getting depressed and exhausted.*

*If it was for a short period it would be OK, but it could go on for ten years, and it is an awful burden to put on a family.*

*I have no children, therefore have no choice, but I would not want to impinge on the lives of others.*

One person suggested that the option of moving in with one’s children may be harder for a woman, if she has been accustomed to looking after the home, than for a man.

Some were very keen not to impose their wishes on their children, but they would welcome care by their children if the children wanted to offer it.

*I don’t want them to feel they have to look after me, but I’d love it if they did.*

A commonly expressed view was summed up by one woman:

*I would want them to care for me, but not be my carer.*

Those who could envisage being cared for by their children were sometimes concerned about the need for support for those who gave that care within the family:

*I think there needs to be help for children to look after parents – like there is when you look after children. Also they need to be taught the technologies of how to look after someone – how to lift. Practical things.*

Some participants had seen or experienced the stress that caring for older relatives could cause families and therefore viewed intergenerational family care as simply too stressful. On the other hand, some who had seen it work in a positive and mutually satisfactory way were more open to the possibility.

© King’s Fund 2005 29
Some participants felt that it was positive for there to be some distance between the older person and their family but not too much. They wanted to give the younger generation space while still being near enough to be able to be there for them. Members of the Irish group saw this as being ‘just motherly’.

Participants suggested that in some cases, children might actually prefer to live very near their parents, so that they could offer whatever care they were going to offer more easily:

_We've decided to sell our house so we can live nearer to my mother. She's always said she doesn't want to live with us. She's chosen the residential home she wants to live in – she's shown us the brochure._

**What participants expected would happen**

Regardless of people’s individual wishes and preferences, few expected their children to be their main carers. Typical comments included:

*Children now are all over the place – they go to Australia.*

*You can’t have a care system depending on your children.*

However, there were some cultural differences. Members of the African-Caribbean group had different expectations and experiences, and some older people in the group were already receiving care from their children. Members of the Bengali group also felt it was desirable for the child to care for the parent, but were very aware of social changes that had impacted on the likelihood of this happening for them:

_The world is changing fast. If a person’s son lives with them, it would be better. If he goes away, he can’t help, and that is what is happening nowadays._

_Although the culture supposes that children will look after parents, there is no guarantee._

Two members of the Bengali group felt that their family had a duty to look after them but they wanted other help too, so that family members were not solely responsible.

In the Chinese group, a significant minority expected their children to look after them, although many more would like them to do so but did not expect that they would.

**Changing roles**

Participants across the focus groups for all cultures reported that they had grown up with an expectation that they would care for their parents but did not think that their children had that expectation.

The Bengali group were particularly aware of change:

_Back home when we were young, it was obligatory to look after parents – here it's totally different. If there were help available, that would be better._

_A long time ago, if a father abandoned his children or children abandoned their parents, then it was very unusual. Now it's not surprising – it's normal._
The Chinese participants also reported major changes:

The traditional view, in the parents’ generation, was that it was expected that children will would look after their parents until the end of their days. Now it is expected that the children will study hard and get a job, and especially professional qualifications.

The participant above felt that their children were less likely to be able to look after them if they were working in professions outside the home. They also gave the impression that they were very supportive of their children’s educational and professional aspirations and did not want to adversely affect their careers with an expectation of heavy caring responsibilities.

Generally participants felt that there was variety of expectation.

I think it varies: my father wanted to be nursed at home, my mother went into a home. It’s choice.

I wonder if the difference is whether you come from an urban or rural background. There’s such variety among people – I’m not sure it’s generational. People talk about future care more nowadays.

Discussing future care

Participants generally considered discussing their future care plans and wishes with children to be too difficult. Some said that they had discussed funeral arrangements but not care arrangements. Observing that ‘families don’t like to discuss the future’, one participant said that she had restricted her comments to telling her family:

I don’t want to be all woollied up and have hair sticking out of my face.

One seminar participant talked about living wills, and the likelihood of there being more of these in the future. Another thought that, with lasting powers of attorney, more people would think about what they wanted in advance, so there would need to be more discussion. Another, however, raised the issue that her parents had changed their minds about the level of disability they could live with as they grew older, and had adapted to the change.

Looking after one other

Another issue discussed was that of older people – such as spouses or brothers and sisters – looking after each other. Participants remarked that brothers and sisters no longer lived together in old age because they were more likely to be separated over distance. However, single people were seen to support each other.

One participant’s mother had been much happier once she moved into a residential home because she had been lonely and now had emotional support from other residents, who ‘looked out for each other’. Another participant said that, both his parents had new partners, and that their partners would now look after them. Some members of the Chinese group referred to members of the community helping each other.
Residential facilities
Most people strongly disliked the idea of residential care and had firm intentions to stay out of it if possible. This view was a result of fears about loss of independence and about standards of care available.

Independence and personal identity
For many, going into residential care was inextricably bound up with an irreversible loss of independence. Most participants dreaded this, and some said they would prefer their lives to end than have to accept residential care.

I would hate a care home – I'm fiercely independent.

It's also about being surrounded by your own things. You lose your identity if you move into a care home.

Standards of care and facilities
Many participants were deeply concerned about standards in residential care, and did not expect them to improve significantly in the future. They saw homes as carrying a stigma, regardless of whether the care was paid for by the individual or the local authority. Participants were also worried about the affordability of good residential care, and feared that they might only be able to afford inferior care.

Maybe you wouldn't even have your own room. My grandmother had to share with three other old ladies.

You hear horror stories about residential homes. I was worried about my mum having to go into a home. All I could think about with my mother was, ‘How am I going to afford a decent home? How much are you talking about in terms of money?’ My mother was in a lovely home but because it was in a lovely location, they sold it off and social services moved her to a place by a railway line.

Many participants mistrusted care homes and their owners, seeing them as just there to make money. However, one had a friend who had gone on to run a home after being an inspector. They said that the facilities there were excellent and that residents were enabled to make their own choices.

Concerns about the quality of residential care staff were common:

The staff are young. They don't have the life skills, or anything that connects them with the people they support.

Most participants wanted care home staff groups to consist of people across a wide age range.

Some participants were concerned about having to share facilities with people who had problematic behaviours, possibly related to dementia. Although they sympathetically acknowledged the needs of people with dementia, they felt it was not in anyone’s interest to integrate those with dementia with those who were more mentally alert.
Benefits of residential care

Some participants were more positive about residential care, and expected standards to improve in the future. However, they could still foresee potential difficulties in accessing the best residential care.

There are some excellent homes. In my area, there are self-contained flats, and they are part of the residential home, and they’re beautiful. If you have the money, you can have one. The Commission for Social Care Inspection and the introduction of care standards have made a big difference – for example, for everyone to have single rooms.

Some participants felt they might become more open to residential care as they became increasingly frail. Describing their current aversion to residential care, one acknowledged:

I feel like that now, but there comes a point when you don’t have the energy.

Another stated:

I’d like to be at home as long as possible. But yes, if it involved being surrounded by loving people, maybe it would be OK.

Some groups spent time discussing what would make residential care more acceptable, including relevant activities and leisure pursuits such as exercise, board games, alternative therapies and facilities such as individual rooms and en suite facilities. Members of other groups made practical suggestions, including trial visits of up to a month, and ‘buddy’ schemes to pair up new residents with more settled residents.

Members of the Chinese group had a number of culturally specific requirements, including a Chinese television channel, Chinese reading material, Chinese music, singing or karaoke, and exercise including tai chi classes. They also stressed that having access to well-prepared Chinese food would go a long way to offsetting other considerations.

Respite care

Participants had more positive attitudes to respite care than to long-term residential care. They also saw respite care as a chance to try out residential care.
Older people with dementia

Participants felt considerable concern about the needs of people with dementia, and those around them:

- People with early dementia don’t get a chance to go to day centres.
- People looking after people with dementia need training in how to look after them.
- There are issues about guilt for people living around the person with dementia – what are the implications for the community?

For the middle-aged participants, the issue of managing risk was very important, and was closely allied to the wider issues of choice (see p 17–18). Some wanted to be allowed to accept the consequences of their actions, whether or not they were mentally alert. Others were not so sure:

- Often, people will admit they are not safe, but how it is resolved is another thing. Maybe you would need the option of a live-in carer. If I became completely ga-ga, you shouldn’t take any notice of me!

There were differing views on the care offered to older people with dementia.

- It depends on the kind of disability. Both my maternal grandmother and mother had senility but were physically fit. My grandmother climbed out of a window in the middle of the night. When she then fell over, her physical injuries were dealt with but not her senility.

- My mother is 91 years old and has painful arthritis, but I feel if she had dementia she might get more help, as she is seen as being in a ‘safe environment’.
Issues for black and minority ethnic older people

Most groups were aware that access to services and needs for services might vary across different minority ethnic groups. Discussion on these issues was particularly important in the groups made up predominantly of black and minority ethnic participants.

Although participants recognised that there were some culturally specific needs, few wanted those needs to be met by providing separate care facilities. In fact, they considered that availability of and access to other specific culturally appropriate facilities, such as Chinese supermarkets, were much more important.

When the participants in the African-Caribbean focus group were asked whether they wanted to be with other African-Caribbean people, most said that they did not.

I have a mixed group of friends – white, Indian....

Language, however, remained an issue for some. The Chinese group raised their need for interpreting and translation. The Bengali group felt that if a person was 'reasonable', they would willingly accept care from them, and that included a person 'of another race'. However, they were concerned about the issue of communication as some middle-aged or older Bengali people do not speak much English.

Participants generally agreed that it was particularly important for people to have choice enabling them to meet their religious and cultural needs. One stated:

Yes – we need lots of choice. Care services should be culturally and gender sensitive. I want to be independent for as long as possible, and I want to die at home. I don't want to die amongst strangers, even if I have to die alone.

Some of the white British participants in the groups were aware that religious groups and ethnic minorities may have their own support systems. They were generally unaware of what existed, though some were aware of Jewish Care as a major provider of services.

The Irish group was concerned at the low level of awareness (even in London) of the cultural needs of Irish people. They felt that these issues were often overlooked, referring to the Irish as a 'hidden minority'. They would want care managers to know that they were Irish and to have an awareness of what that meant to them. As we have seen (p 16), the Irish group felt it would be particularly important for service providers to provide or prepare Irish food for them. They would also want Irish newspapers in a residential home, and would want access to Irish music:

If you put on Irish music, people will start foot-tapping however old they are.

Overall, people seemed to want to be integrated with members of other cultures and ethnic groups, but they did want their cultural needs to be taken into consideration too.
Changing expectations

It is often said that the generation that is now in middle age will be more assertive and more aware of their rights as they get older than the previous generation has been. As a consequence, their expectations of care services for their own future may be radically different. In view of that, we were interested to know whether participants thought that their expectations for their own old age differed significantly from those of their parents. The great majority felt that there were major differences, but not everyone agreed on what these differences were.

This was a very complex issue for many, since some participants in almost all of the groups (most notably in the Irish, Chinese, Bengali and African-Caribbean groups) had grown up in a different country and/or culture to that of their parents. Thus, they were comparing their experience of a new country (or continent) with what they knew, but had not always observed, of the time and place in which their parents grew up.

Some felt that their lives in the UK were at times better, and at other times worse, than the lives of their parents. One African-Caribbean participant explained:

I like to go out and experience different places. This is how you enjoy life. I like to know what is going on in the world. You will live a happier life if you have different experiences. My parents only worked and couldn’t go anywhere. They died young. But in the West Indies, you could go from home to home and stay in different people’s houses. Here, it is like a prison cell. You shut the door and you can’t hear anything.

Many participants felt that their expectations for their health were higher than that of their parents, and that mental attitudes were different – for example, in seeing themselves as being young for a longer period.

We are not old at 60. They were in poor health once they got to 65 or 70 years. We expect to be healthier.

Our generation may find it easier to keep young for longer. The older generation wore black bombazine from 55! But my mother surfs the internet and uses a mobile.

One of the women in the Chinese group spoke of her 87-year-old mother who was living alone in Hong Kong with no help other than medical check-ups. The group member considered herself to be more fortunate than her mother, because she had access to support. However, some participants who had migrated from other countries felt that their health was poorer than that of their parents. The Bengali group felt particularly strongly about this, as one participant described:

Physically, and in other ways, things are going down, and I expect it to get worse than it is now. My parents had no diseases, and they just died of old age but I am suffering more.

Many participants in the Chinese group were very appreciative of having greater opportunities than previous generations had:

In our parents’ day, life was harsh, with no electric supply. We had to grow our own vegetables, otherwise there was no food supply.
However, they were also aware of losses to their cultural heritage, which they felt was becoming fragile. Another Chinese participant explained:

*Our parents’ generation, due to shortage of material wealth, tended to have to work hard and have large families. And for special events, such as Chinese New Year, there are special foods – dumplings – and in their day, our parents knew how to make them. But our generation has to buy them, and the skills are being lost.*

The Chinese group members were particularly thankful for technology such as the internet. They saw electronic media as playing an important role in helping them achieve an old age in which they would be well served culturally – for instance, through access to Chinese digital television, if they could afford it:

*In my parents’ days, life was simple, yet difficult. Not everyone had a TV or radio. There were no community activities, as such.*

*If you look back, our parents’ lives were more routine, and there was less entertainment (TV, video and travelling). The elderly play mah-jong – a very popular game.*

Some participants in the other focus groups also pointed out differences in material wealth:

*Our parents had plans – to do with finance – and we should be better off than our parents. People have more now.*

One participant raised the possibility that the generation who were about to become old were less able to enjoy retirement:

*People work hard (for instance, bankers in the City) and have no hobbies or outside interests, so what do they do when they retire? Our parents had a wider spectrum of interests.*

Others felt that attitudes about independence and dependency had altered:

*We’re more self-reliant. We don’t want to be a burden.*

*We travelled and made provision.*

One of the Chinese participants noted that her parents need someone to accompany them wherever they went, mainly due to language problems. She, on the other hand, had more freedom to be independent.

Other participants felt that there had been a major shift in women’s lives, which would greatly affect expectations:

*Our expectations are higher – especially as women. This generation has better jobs and education, and we expect more.*

*If women didn’t work, they thought they didn’t deserve a pension and saw it as charity. We see things more in terms of rights. I have paid, and I expect to get something for it.*

Some participants felt that they might share the same principles as their parents – for instance, the desire for independence – but that what this meant in practice would be different:
The principles are the same – my mother didn’t want a computer, but she wanted her version of independence – no care home, as she didn’t want to be away from her friends. I might be better informed, but my needs will be similar.

Others felt that they did have higher expectations than their parents, in terms of longer life expectancy, better health and expectation of choice, which they felt was greater than ever:

*My parents had no aspirations for care. They didn’t expect to live that long – and they didn’t. Further back, people expected to go to the poor house or die.*

*I want lots of choice – a care village with lots of social life. We will have higher expectations but the issues will be much the same.*

One participant, however, said they were torn between their high expectations and what they actually knew was available. Another felt that people with higher incomes tended to have greater expectations than those with lower, and were probably more likely to realise them.

Some participants felt that social cohesion in local communities changes as society becomes more affluent. They felt that in the past, people’s needs would have been met by friendly neighbours, and that society should find a way to re-create this system.
Priorities and suggested improvements

When participants discussed their personal priorities for improved care services in their old age, their key priorities were:

- to have services that enabled them to maximise and retain their independence
- to be valued as individuals and not stereotyped because of their age.

Many participants stressed the value of low-level preventative services, and wanted access to cleaning and maintenance as much as – or more than – they wanted personal care. They also frequently mentioned the importance of a good GP service, with much nostalgia for the era of home visits to older people. Some wanted health and social care to be more coordinated, and felt that the division between these services was unhelpful from the point of view of the service user. They also wanted services to be delivered by fewer people, who were appropriately multi-skilled and trained for the purpose, within a system that was less bureaucratic and more generously funded than they perceived current services to be.

The highest priorities of many participants were issues that are not conventionally viewed as ‘care’ services. They saw improved transport for all, and better leisure and educational opportunities, as essential underpinnings of effective care. Several also liked the idea of advocates to help older people obtain their entitlements.

Participants often mentioned that they wanted care service decisions to be less influenced by budgetary and organisational constraints. They wanted to see a more independent approach both when assessing people’s needs, and when monitoring and inspecting services. Above all, they wanted respect for their individuality and to be in control of how they were helped to live their lives as fully as possible.

Seminar participants prioritised care service options as follows:

- services that promote or maintain independence rather than elements of care
- services such as social life and leisure to enable clients to remain intellectually active, for instance using a computer and getting out and about
- income
- service choices that could be adapted to the client’s time of life and level of need.

Their overall ranking of service options was as follows:

1. regularly eating your preferred food
2. 24-hour, on-call service for help and emergencies
3. a weekly or monthly visit from an odd-job person
4. basic dusting and hoovering
5. sufficient space for one’s possessions
6. assistance with bathing at times selected by the client
7. access to qualified tutors or teachers for activities
8. help with heavier cleaning and maintenance tasks
9. someone to spend time with and talk to
10. a personal advocate
11. one’s own sitting room as well as a bedroom
12. movement sensors to ensure safety within the home
13. daily transport to local shops
14 free access to comprehensive digital television
15 parking for visitors
16 someone to do the washing
17 access to a gym, swimming pool or hydrotherapy pool
18 someone to take them for a walk
19 weekly transport to local shops and other facilities.

When forced to prioritise, none of the participants chose the following options, which might be viewed as ‘luxury items’:
- breakfast in bed
- door-to-door transport
- one’s own courtyard or outside space
- gardening services
- dog-walking services
- a spare room
- three menu choices at main meals.
Conclusions

This project required participants to consider what they would want and need in circumstances that were difficult to imagine and, to some extent, unknown. Despite these limitations, there were some clear messages about what participants felt would be most important to them as they grew older, and about how their needs and expectations differed from those of earlier generations.

CHOICE

One key message was that people expect to have their individual needs and preferences accommodated and catered for. This is a generation of people who have generally had choice in most aspects of their lives, from food in supermarkets and restaurants to television and radio channels, holidays, and even – more recently – public services. Some stressed the need for a reasonable income if they were to continue to exercise choice in the way in which they had become accustomed, and there was much concern about whether they could afford the lifestyle they might choose in old age.

SOCIAL CONTACT

The importance of social life, and the need to maintain this, came across very strongly in all the groups. To many, friends appeared to be as important as family, and participants frequently expressed the desire to stay mentally active and stimulated. Some also emphasised the social aspects of receiving care, feeling that it would be important to be able to communicate and interact with paid carers and others who supported them when they were older.

INTEGRATED CARE

The interconnectedness of security, home care, health, personal care and social life was a key theme and many participants expressed the importance of these not being seen as separate domains. Having a clean, well-maintained home and good social networks would be essential to their sense of security and to their physical and mental health.

ATTITUDES TO CARE BY CHILDREN

A very strong message from all the groups was that this generation did not expect their children to look after them when they were older. Many did not even want this, as they did not want to be a burden or restrict the lifestyles and prospects of their younger family members.

CREATING COMMUNITIES

There was some discussion in the groups about the need to re-create different kinds of communities that were perhaps similar to what had existed in the past. Such communities would need to facilitate intergenerational care and support, and to provide homes for life – or, at least, for people in their 50s and upwards.

DISCUSSING PLANS FOR THE FUTURE

A number of groups highlighted the need for more discussion with friends and family about future care preferences and aspirations, downsizing, and preparing for old age. However, many raised the difficulties of raising these issues with families, and some may...
need help to do so. In particular, there was considerable concern about the needs of older people with dementia in relation to how their carers could look after them, and how families could accommodate their wishes.

**LONDON AS A PLACE TO GROW OLD**
The question of whether London was a good place to grow old was inconclusive. Some participants were very positive about the benefits to older people of living in London, while others thought it would be lonely, and that services were worse than elsewhere. The literature review (Levenson and Joule 2004) showed a wide range of service quality and experience depending on where people lived, and participants’ different views may have reflected their own choices or personal experiences of services in particular London boroughs.

**Looking to the future**
There is some consensus among middle-aged people about what they will need when they are older. There is an aspiration that their individual preferences and needs will be accommodated within future care services and a very strong desire to remain in their own homes, supported by a range of services, including help with housework and maintenance.

It remains inconclusive whether middle-aged people’s aspirations will lead to piecemeal reform or to a radically different picture of care services for the future. These participants clearly saw themselves as having longer lives, and more extended better health, than their parents’ generation. On the whole, they also saw themselves as more assertive and demanding of public services. However, they were concerned about their ability to finance themselves through a long old age.

A very strong message is that members of this generation do not expect, or want, their children to look after them when they are older. As a result, there is a need for greater discussion with families and friends about what they do want for themselves when they are older, and how to prepare for that, so they can live their old age in the way that they choose.
References


We used this topic guide flexibly, and differently with each focus group, to cover a broad range of material while exploring each group’s priorities. It evolved as we gained experience from using it with previous groups.

SETTING THE CONTEXT
We all expect to have good old age and a long retirement, but we eventually may need care or help – for example, in:
- cleaning and shopping
- cooking
- getting around
- getting washed and dressed
- ensuring safety
- maintaining social contact.

PRINCIPLES FOR IDEAL CARE
- What would a really good care service look like?

MAKING CHOICES
- Where do you think you may be living (list options if prompt needed):
  - independently?
  - with family – how many people expect to be looked after by family (or friends)?
  - sheltered housing?
  - care home?
- How do you think you might spend your days?
- How might this be different to your parents’ generation’s experiences and expectations?

WHAT IF...
- What if you can’t walk far or leave your house?
- What if you don’t have friends or family nearby?
- What if your memory is very poor, or you become easily confused?
- What if you don’t see or hear well?
- What if you can’t make yourself understood?

SERVICES
In these circumstances, what would help you manage better?

TRADE-OFFS
Use one or two scenarios.

PAYING FOR SERVICES
What should you pay for, and what should the government provide or pay for?
CONCLUSIONS

What care service or service improvement would you most like to see?

We used two types of scenarios: case study scenarios, in which participants consider the situations of fictional individuals, and settings scenarios, in which participants consider situations in which they might find themselves.

Case study scenarios

LILA

Lila is an Iranian-born woman who has lived in the UK for many years. She is 76 years old and worked as a public health consultant until her retirement at 62. Her husband died many years ago, and her two daughters live in the United States, where they hold academic posts.

Lila has been active in her retirement, but a recent stroke has left her with very limited movement on her left side, and slightly slurred speech. She is usually mentally alert, but since the stroke she has found reading difficult, partly due to poor vision, and partly because she easily becomes tired and unable to concentrate.

Lila has been using her pension and savings to buy in-home care, but even though she has considerable savings, she is not sure that she can afford to keep paying for this level of support. She would like to stay in her own home if possible.

- What services might suit her, if they were available?
- What services should the council provide and fund (subject to assessing her means)?
- Are there other services that she might want to buy for herself?

FRANCES

Frances is single, aged 80, and has always lived in London. She was a noted champion of older people’s rights, following on from a career as a trade union official. For the past year, she has been neglecting herself, and a psycho-geriatric assessment has indicated signs of dementia. However, she is still very strong-willed and refuses to discuss her future, as she is very aware of inadequacies in local services and does not see herself as being comfortable using any of them.

- How can she be helped to stay at home?
- At what point (if any) do you think she might be better off elsewhere?

MAUREEN

Maureen, age 69, was born in Cork, but came to London to work as a nurse when she was 18, and has lived here ever since. She has three children and three grandchildren. The family is close except in the geographical sense, as two of the children, and all three grandchildren, have moved to Yorkshire. One son, who lives in London, is unmarried and frequently travels to the Far East on business – often at short notice.

When Maureen was 50, she and her husband separated and she became a lesbian, though has never since had a live-in or long-term partner. Her children have been accepting of her decisions, but several of her former friends were shocked and lost contact, while many of the new friends she has made are considerably younger than herself. Maureen is still fit and well, but is looking to plan for her ‘next 30 years’, as she puts it.

- What might Maureen take into account in making choices?
MARIANNE
Marianne, aged 78, came to London from St Kitts as a young woman, just after getting married to Derek, who died last year. Derek was much loved and was also her carer. She has one daughter, aged 56, who suffers from depression, but is still able to help Marianne around the house and comes round to watch television with her two nights a week.

Marianne is very immobile, due to bilateral hip replacements that went wrong, and she also has diabetes and high blood pressure. She needs help with all household tasks and some help with personal care, and she gets a substantial package of care at home. She is adamantly opposed to residential care, saying: ‘I was a care assistant for 25 years, and I know that we never had the time to look after people as I would want to be looked after.’

- What can be done to help her avoid residential care?
- If she does have to go into a care home, what might make her experience better?

Settings scenarios
MOVING AWAY FROM YOUR LOCAL AREA
You are 70 years old. You have decided to go into supported housing, and you are looking forward to it because your house is too large, and you are keen to plan ahead. Your long-term partner died three years ago, but, after a bad year, you have begun to be able to go out again and socialise. You have a lot of friends in the area. You have decided to buy, but, having looked at the options, you realise that you can afford a suitable property with adequate care only if you move out of the area. Do you think you should choose the supported housing that you can afford even if it means moving out of the area?

CHOOSING A CARE HOME
You have decided to go into residential care, but you can’t make your mind up between two homes. Both provide things you want, but both have drawbacks. The first home provides very good food but only offers activities that you know you would hate. In the second home, the food is less good though acceptable, but the residents regularly go on interesting outings. How would you make up your mind between the two?

CHOOSING SUPPORTED HOUSING
You have found a very nice flat that has good security, helpful wardens and spacious rooms. However, it is a long way from your friends and family. Would this be enough to stop you going there? If your answer is ‘yes’, what other factors might persuade you to go change your mind?

PAYING FOR CLEANING
You can manage at home with a little help, and the council gives you some money to buy the help you need from a range of sources. However, the best cleaning service costs a bit more than you want to pay. The only alternative service would come for only an hour a week, and you have heard that they don’t do a very good job. Having the better more expensive service would mean you could afford to go out to meet your friends only every other week instead of weekly. Which service would you choose?

CHOOSING A DAY CENTRE
You have been invited to attend the local day centre. On a visit, you noticed the staff were very friendly and the lunch was good, but you don’t think you’d have much in common with the other users of the centre. Would you go?
Appendix 3: Participant data

There were 63 participants in the focus groups, divided into seven focus groups. A total of 84 people participated in the focus groups and/or the seminar, and 23 participated in both. The figures below relate only to focus group participants.

**GEOGRAPHICAL SPREAD**
Participants, by postcode area

<table>
<thead>
<tr>
<th>Postcode Area</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>East London</td>
<td>20</td>
</tr>
<tr>
<td>South-east London</td>
<td>14</td>
</tr>
<tr>
<td>Romford</td>
<td>3</td>
</tr>
<tr>
<td>West London</td>
<td>10</td>
</tr>
<tr>
<td>North-west London</td>
<td>4</td>
</tr>
<tr>
<td>Surrey</td>
<td>3</td>
</tr>
<tr>
<td>Dartford</td>
<td>1</td>
</tr>
<tr>
<td>South-west London</td>
<td>2</td>
</tr>
<tr>
<td>Harrow</td>
<td>1</td>
</tr>
<tr>
<td>Uxbridge</td>
<td>1</td>
</tr>
<tr>
<td>Enfield</td>
<td>1</td>
</tr>
<tr>
<td>Not stated</td>
<td>3</td>
</tr>
</tbody>
</table>

**AGE RANGE**
The full age range of participants was 45–81 years, although the majority were 50–59 years. The Bangladeshi group was slightly older on the whole, although it included the youngest of all participants. The African-Caribbean group was also older.

**GENDER**
Of the participants, 47 were women and 16 men.

**ETHNICITY**

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>African</td>
<td>1</td>
</tr>
<tr>
<td>African-Caribbean</td>
<td>7</td>
</tr>
<tr>
<td>Asian other (born in Zanzibar of Indian parents)</td>
<td>1</td>
</tr>
<tr>
<td>Bangladeshi</td>
<td>6</td>
</tr>
<tr>
<td>Chinese</td>
<td>15</td>
</tr>
<tr>
<td>Irish</td>
<td>2</td>
</tr>
<tr>
<td>Mixed white/black Caribbean</td>
<td>1</td>
</tr>
<tr>
<td>White British</td>
<td>24</td>
</tr>
<tr>
<td>White other (French)</td>
<td>1</td>
</tr>
<tr>
<td>Not stated</td>
<td>5</td>
</tr>
</tbody>
</table>
EMPLOYMENT STATUS
Thirty-one participants were in paid work, 26 were not in paid work, and six did not state their occupational status.

OCCUPATION
Participants had a wide range of occupations, ranging from housewives to seamstresses and tailors, from academics and researchers to secretaries and administrators.

DISABILITY
Twelve out of 63 participants (19 per cent) considered themselves to have a disability.

CARERS
Nine out of 63 participants (14 per cent) were carers.

We used this exercise to find out more about participants’ priorities for care services. The aim was to see if there is any agreement over what would be essential and key priorities for older people in the future. We also wanted to discover what participants’ priorities actually were and what kinds of issues they would consider when making choices.

**Tools for the exercise**
On your table, you should find the following:
- a set of 38 cards (35 with different service choices and three blank)
- a list of the 35 service choices for each person at the table
- some Blu-tac.

Around the room are five flipcharts, each headed with a category as follows:
- clean and well-maintained home and garden
- food and drink
- social life and leisure
- keeping healthy (mentally and physically)
- personal care.

**The task**
Participants at each table have to decide on their top 12 priorities out of the 35 choices listed below. If your top priorities are not included in the list, add up to three further service options (on the blank cards). There must be at least one service choice in each of the five categories above, though it’s up to you which services fit into which category.

When each table has decided and agreed on its 12 choices (which we expect to take about 45 minutes), one person from each table will stick the chosen cards to the relevant flipcharts. You may like to note down key issues that arise in your discussions during the course of the exercise, as we will be having a feedback session afterwards.
Service choices
(Note: All services are presumed to be of a very good quality)
- access to a good selection of films (including in a range of languages)
- access to a gym, swimming pool or hydrotherapy pool
- access to independent financial, legal or other advisers
- access to qualified tutors or teachers for activities such as pottery, art, yoga, or tai chi
- access to snacks outside of main meal times
- an annual outing outside England
- assistance with bathing when you want it
- basic dusting and hoovering
- breakfast in bed
- daily transport to local shops or other facilities
- free access to comprehensive digital television
- free email and text messaging
- help with heavier cleaning (such as curtains) and maintenance tasks
- monthly outing in or around London
- monthly visit from odd job person
- movement sensors inside to check safety within own home
- 24-hour on-call service for help and emergencies
- one’s own sitting room as well as a bedroom
- parking for visitors
- personal advocate
- regular access to your chosen hairdresser
- regularly eating your preferred food
- someone to do your washing
- someone to spend time and talk
- someone to take you for a walk
- someone to take you shopping rather than doing it for you
- someone to walk the dog
- space enough for own possessions (including furniture)
- spare room
- three menu choices at main meals
- weekly massage
- weekly transport to local shops/other facilities
- weekly visit from odd job person
- well-maintained and nice garden
- wine and beer with meals.
Other publications for the Care Services Inquiry

The Business of Caring: King's Fund Inquiry into care services for older people in London
Janice Robinson and Penny Banks

Concerns about the care system for older people have been commonplace in recent years. Aware of these concerns, the King's Fund established an Inquiry into the way in which care services are provided for older people in London. Drawing on the experience of older people and their carers, care staff and managers, regulators, and commissioners, the year-long Inquiry concludes that there are major shortcomings in the current care system that disadvantage older people and their carers. This report of their findings calls for investment in market development, reform of social policies and mobilisation of more public and private resources.

ISBN 1 85717 490 0 Jun 2005 106pp £25.00
Download summary at www.kingsfund.org.uk/summaries

Trends in the London Care Market 1994–2024
William Laing

The demand for care and support in old age is growing nationally, but London faces some particular challenges. For example, although there are fewer older people in inner London, many are likely to need social care as a result of poor health, poverty, poor housing and lack of social support. This paper shows how London differs from the rest of England, examining past, present and future trends in its population profile, and in the resources and services available for older people. It casts light on some controversial issues such as levels of expenditure on residential and home care services, and finding care home places for older people outside the London area.

ISBN 1 85717 491 7 Jul 2005 96pp £20.00
Download summary at www.kingsfund.org.uk/summaries

Commissioning Care Services for Older People: Achievements and challenges in London
Penny Banks

What services are available to older people is determined to a large extent by how care is commissioned locally. This paper examines how care is being commissioned in six London boroughs, and how local authorities are working with their primary care trust partners, to transform the mix of services on offer. It shows how service users are involved, and assesses the extent to which commissioners understand and manage the market and respond to need. It also highlights factors that are helping or hindering commissioning practice across the capital.

ISBN 1 85717 492 5 Jun 2005 22pp £5.00
Download the full paper at www.kingsfund.org.uk/publications
Understanding Public Services and Care Markets
Ann Netten, Robin Darton, Vanessa Davey, Jeremy Kendall, Martin Knapp, Jacquetta Williams, José Luis Fernández and Julien Forder

Most formal care services for older people are funded by the public sector, but they are largely supplied by independent providers. This paper looks at what factors influence the ‘mixed economy’ of the care market – including what funding is available and from where, and how commissioning works – and the role played by service users. It also examines how markets for home care, care homes and extra care housing work; how the market performs as a whole; and how policy and practice should be developed.

ISBN 1 85717 494 1 Jun 2005 48pp £6.50
Download summary at www.kingsfund.org.uk/summaries

Related publications

Auditing Age Discrimination: A practical approach to promoting age equality in health and social care
Ros Levenson

How health and social care organisations respond to the needs – and rights – of the UK’s growing numbers of older people is increasingly in the spotlight. The Government’s 2002 National Service Framework for Older People has put age equality firmly on political and health service agendas, and new scrutiny groups have been set up at local level. But age discrimination is difficult to define and challenging to combat in practice. This guide gives clear, practical guidance about how to gather and assess evidence of age discrimination, who to involve in the process, what kinds of evidence to look for, and where to look.

ISBN 1 85717 472 0 Feb 2003 70pp £15.00

Future Imperfect: Report of the King’s Fund Care and Support Inquiry
Melanie Henwood

Across the UK, some one million people – many of them women – provide care and support services. Their work is critical to the health, well-being and quality of life of the growing numbers of people who rely on their help, including older people with disabilities and mental health needs. This report, based on a far-reaching investigation into the care sector, paints an alarming picture of a service faced with growing demands as the numbers of people needing help grows, and the complexity of their needs increases.


Old Habits Die Hard: Tackling Age Discrimination in Health and Social Care
Emilie Roberts, Janice Robinson and Linda Seymour

Based on a telephone survey of 75 senior managers in hospitals, primary care groups, community trusts and social services departments, this report shows that managers in the NHS and social care organisations support new moves to combat age discrimination in health and social care, but lack the tools they need for the job. It provides guidance on practical ways to implement policies designed to prevent age discrimination.