

**Maintaining Independence In Later Life:
Older People Speaking**

A Report By
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CHAPTER ONE: Introduction

"I know it's old, it's damp and my roof wants doing - it leaks, It's in a mess, I can't afford to pay for it, but I'm not going to leave it... I've always lived in it. They reckoned it was cold and that to live in, but if you've always lived in it, you don't bother, do you? They keep telling me it's old fashioned - but it's an old house" (quoted in Harrison and Means, 1990, p63)

Policy makers are increasingly appreciating the importance of housing and home to old people, and how this links to their desire to maintain their independence, This study is an important contribution to this debate in that it focuses upon how older people themselves think about and talk about these complex issues, and how this relates to their existing housing and support situation,

Thirty one households composed of 39 older people were interviewed from four different localities, These were a large midlands city, a city in the south west, two London boroughs and a market town with surrounding villages in the north west, The age range of the respondents was from 60 to 98 years, Twenty households were owner occupiers and 11 rented, Ten were in sheltered housing (now increasingly called retirement housing), of which 4 were private schemes and 6 were rented, The appendix provides more detail of the sample, and how the sample was drawn,

The next chapter locates this group of older people within a broader demographic and policy context, Chapter three focuses down upon what they had to say about home and independence, chapter four looks at the support they received from both family and friends as well as from more formal services, and chapter five concentrates upon their perceptions about the strengths and weaknesses of their present housing situation, The final chapter reflects upon their views about their overall quality of life and how this relates to their concerns about service gaps and other worries,

The picture which emerges is of the great diversity and creativity of older people, The vast majority of those interviewed sought to maintain their independence on a day to day basis in a way which minimises their demands upon family, friends and social services, It is also a picture of people who often face their increased dependency and the pain of bereavement with great courage, Finally it is a picture of people who need a more imaginative response to their emerging needs than is sometimes available,

CHAPTER TWO: Setting the context

Introduction

Our respondents are living not only in times of great demographic and economic change, but also in a period of major policy shifts in terms of housing, health and community care. This chapter gives a brief snapshot of some of the main elements of these changes.

Demography

The proportion of older people in the population has risen steadily during the twentieth century (Rolfe, Mackintosh and Leather, 1993a). At the time of the 1991 census, 18.4% of the population in England and Wales was of pensionable age, representing 9.4 million people of whom 3.6 million were over 75 years.

Three key trends are predicted for the future. First, there will be an ageing of the elderly population in the short to medium term so that the number of people aged 85 or more will rise sharply, including a predicted rise of 217,000 in the first decade of the next century. Policy makers see this as highly significant because the 'old old' experience higher levels of illness and frailty than the 'young old', and so they tend to require expensive health and social care services.

Second, the ageing of the post war baby boom generation will take place over a slightly longer time frame so that by 2031 it is projected that 26% of the population will be over pensionable age. Policy makers are interested in this development because of the public expenditure implications, especially in terms of pension rights.

The third trend relates to an ageing of the minority ethnic population. "Non-white" people made up only 1.1% of the over 65 population in the 1991 census. However, the next census is likely to uncover a very different picture, for as Blakemore and Boneham (1994, p 17) point out:

Rates of increase will be rapid, especially over the next 20 years as the cohorts of migrants of the late 1950's and 1960's reach retirement age. Already the number crossing the frontier of 60 years of age represent the fastest-growing age group in the black community. The population of black and Asian people in the age group immediately before retirement (45 - 59/64) is substantial (16 per cent in 1987-9) and suggests a four or five fold increase among the pensionable age group by the year 2000.

This predicted development has received little interest from policy makers.

Income and wealth

It is known that the incomes of elderly people have risen in recent years. Hancock and Weir (1994) have estimated that average real incomes of pensioners were 25-30% higher than ten years earlier. However, they point out that these increases were less than for non pensioner households and such figures obscure inequalities within the elderly population. Gaps between the rich and poor, older and younger pensioners and those with and without occupational pensions had all grown. The most important component of personal wealth in later life is the home equity of owner occupiers. However, Rolfe, Mackintosh and Leather (1993) warn that it is easy to overestimate the extent of these resources and that less than 25% of older people had high levels of home equity.

Accommodation

A considerable amount is, also, known about the present and likely future tenure profile of elderly households. They are less likely than those in mid-age to be owner occupiers, but ownership levels amongst elderly households has been rising steadily and is projected to reach 66% by 2001, and this will represent 3,8 million households of whom one third will be over 75 years of age (Rolfe, Mackintosh and Leather, 1993a). Older people are more likely to rent than the rest of the adult population, with the 1991 census identifying older people as the head of the household in 46% of council homes and 44% of housing association properties. Future trends will be heavily influenced by the levels of central government support for social renting and private renting. Approximately, nine per cent of older households live in some form of sheltered or retirement housing to rent or own, and there were just under half a million sheltered housing units in England in 1992 (Tinker et al, 1994 and see, also, McCafferty, 1994),

Only a minority of older people live in residential and nursing home care. There were just 556,300 places for elderly people in residential care, nursing home care and NHS long stay provision in April 1994 (Laing and Buisson, 1995, p17) and it is estimated that "another 72,000 places will be needed to keep pace with demographic change by the turn of the century" (p50). The independent sector increasingly dominates the provision of such places,

Housing, health and community care: key policy trends

Housing policies

The dominant housing policy since 1979 has focussed on the need to encourage owner occupation as the preferred tenure. The declining rented sector has seen an increased role for housing associations and a decreased role for local authorities and the private sector. Housing disrepair and the affordability of housing has remained a problem across tenures (Malpass and Means, 1993). Retirement housing has seen a shift towards a growing emphasis upon it as a potential alternative to residential care, although the hard-to-let nature of a sizeable element of the stock is also becoming clear (McCafferty, 1994),

Community care

The community care reforms brought in by the National Health Service and Community Care Act 1990 placed an emphasis upon the enabling role of social services and stressed their need to develop the role of the independent sector as suppliers of both residential care and domiciliary services (Means and Smith, 1994). The family is still seen as the primary care giver, with the role of publicly funded services being to support their work. The philosophy of the reforms stress the need to move from service driven to user driven responses of the needs of clients, with an emphasis upon the need to develop flexible care packages. However, it is becoming clear that resource pressures mean that it is only those most at risk and these who are most dependent who are likely to receive a service. As a result, services may be denied to those older people whose quality of life is most likely to gain from a flexible housing and support package. The support needs of such individuals risk being unmet until they have a major life crisis,

Health care

The NHS and Community Care Act 1990 also resulted in the development of a purchaser - provider split within health authorities, the growth of NHS trusts and the emergence of fundholding general practitioners. This period has seen a declining role for the NHS in continuing care, which has had considerable resource implications for social services. The growing emphasis upon primary health care has led to an expansion in day surgery and also encouraged earlier discharge for patients from acute hospitals (Wistow, 1995),

Towards a seamless service

A user driven service needs to appear a seamless service from the point of view of the client. Policy reforms have certainly re-drawn the boundaries between health, housing and welfare with, for example, social services now playing a pivotal role in funding what would once have been seen as free 'nursing' care within the National Health Service. However, it is equally clear that there remain tensions between purchasers and providers about how to define and interpret these boundaries at the local level,

CHAPTER THREE: The meaning of home and independence

Introduction

Policy makers and practitioners operate from the assumption that older people wish to maintain home and independence, The focus of this chapter is upon what our respondents understand by the terms 'home' and 'independence', and how this can vary according to such factors as their age, health, resources and their more general experiences through the rest of their life course,

Home as a place of privacy and refuge

Research on the meaning of home suggests that a dwelling feels like home if it has the capacity to be a place of privacy and refuge for the individual (Benjamin and Stea, 1995), Several of our respondents articulated such views, Thus, Mr and Mrs Jones explained their idea of home in the following way:

Mr Jones: It's a place of retreat really,

Mrs Jones: "... and home's always been a place where you want to go back to, however humble it is, Even when we go to town, we're still glad, well I am, to get back... It's a place of our own,

In a similar view, respondents such as Mrs Evans saw home as a place where you could close the door on the outside world and where you could find privacy if that was your choice, so that home "was freedom to do what you want, when you want",

However, the authors were also struck by how the presence or absence of such views, together with the exact form of such views were influenced by a wide range of factors such as length of residence, health status, tenure and outside interests, Not surprisingly, in terms of length of residence, it was those who had lived a long time in the same house who tended to associate feelings of home with living in a particular building, Mrs Young, an owner occupier, had lived in the same house all her life (her parents had originally rented it), She repeatedly stressed that "I just love my house really" and reflected that "I only get out of it for two or three hours and I can't wait to get back", Mr & Mrs Smith had lived in their present home all their married life, Originally, this was as local authority tenants but they had bought the house in 1970 with the intention that "we'd be buried here" since "it ain't a palace but it's ours, you know",

It was not just owners who retained strong feelings about their preference to 'stay put' in their present home, Mrs Saunders was an 89 year old council tenant who had lived in the same 3 bedroomed flat for the last 43 years, She considered a move to sheltered accommodation when her husband was alive but rejected this on the grounds the flat offered was "dark and dingy", She now had no intention of moving because she had "all my home comforts" in the present flat which is in a nice quiet tower block "with no noisy teenagers running all over the place", Another important consideration was the desire to stay close to good neighbours and friends because:

There's one or two people moved out of these flats and they wish they hadn't because they miss all their friends. And you do see people if you go out, either on the bus or in the lift,

Another reason why particular houses evoked such powerful sentiments was their association with people's history such as creating a home or bringing up children,

Not all of those interviewed had lived a long time in their present accommodation, For example, the sample included ten households who had moved into some form of sheltered accommodation and five who had retired to live in their present home, The latter group included those like Mrs Grant who stressed she had chosen the village rather than the cottage with her late husband, and how it was the friendliness of the village together with local shop, "the pub, the church and an excellent medical practice all in one village", which remained the main attraction, On the other hand, Mr and Mrs Booth moved to the same village on their retirement and both noted the same friendliness since "it was an easy village to become part of", but Mrs Booth especially stressed how:

Yes, I love my little cottage, you know, If I won a lot of money I still wouldn't give my little cottage up, no way",

Of those who had moved into sheltered housing, nearly all had settled and now looked upon their present accommodation as their home, Mrs James saw herself as having bought her home to her sheltered flat for rent in the form of her possessions from her previous home, and felt she also gained from moving to a scheme where she already had friends nearby, Others such as Mr and Mrs Wallace and Mrs Evans both stressed how they felt at home in their sheltered flats for rent because they felt secure from burglaries, Sometimes such views were tempered by the fact that not all possessions could be kept because of the small size of most sheltered accommodation,

Similar feelings about their flats and bungalows were expressed by those who had moved into private sheltered schemes, Thus Miss Mills who is 93 had moved into her private sheltered flat seven years ago, She settled in quickly because it was in the same neighbourhood and so she could keep her old friends and go to the same shops, The flat was comfortable, the warden was excellent, having the laundry was a blessing and the scheme generated a feeling of security and safety, She felt it had "started to feel like home when my old friends visited me here",

The two main exceptions to this positive picture were two respondents who had moved because of the health problems of partners, Thus Mr White, an 80 year old who had suffered a major road accident moved with his wife to a private sheltered bungalow and stressed how "I took to this place", His 70 year old wife, on the other hand, lamented how much younger than her neighbours she felt, her resentment at the daily call from the warden and how "when I go out at night... I never see another soul", Mr Wilson had moved from his three bedroomed council house to a local authority sheltered flat, and expressed how small and overheated the flat felt, the lack of other male residents especially in "the female domain" of the common room, and how much he missed his garden, However, his wife had since died and he had suffered a stroke, leading him to reflect that :

Well I... wasn't really happy like I say... because it was an entirely different life to what you had in the house ,, (but) when you health breaks down you think, well better the devil you know than the one you don't, At least I've got established here now, everybody knows me and I know them, so I don't think I'd want the hassle again of ever moving to be honest with you,

This last quote not only identifies the difficulties some people have in re-establishing a sense of home in a new dwelling but also how such situations are not static, Increased dependency or the death of a partner are among the factors which can lead to a re-assessment of the strengths and weaknesses of one's present accommodation, Sadly, this often takes the form of reducing a sense of being at home in one's present accommodation, Thus, Mr & Mrs Smith now feel they need to move to a flat with no stairs because Mrs Smith had Huntington's Chorea, while Mrs Martin's enthusiasm for her house has been undermined by the death of close neighbours and the more general loss of community spirit and facilities within her village, Fear of burglary or the reality of being burgled had undermined the capacity of some to see their dwelling as a place of refuge and retreat, and this had prompted a move into sheltered accommodation for households such as Mr & Mrs Wallace, Major house repair worries could also undermine satisfaction with one's house and so Mr Price expressed unhappiness with his three storey house because repairs were always very expensive as a result of the need for scaffolding, and he was also upset by having to watch a once beautifully tended garden become unkempt,

The meaning of home was not restricted to issues about house and neighbourhood for some of our respondents, Thus, Mrs Goldberg, born in Hungary, stressed that she now saw her midlands city as her home:

My home is (here), People have said because I was born and brought up in Hungary - are you going home for your holiday, I say my home is in (the midlands) and I go to Hungary, I still have friends and relatives there but that is not my home, And quite often it happens, and it happened when I was in Hungary, if I am not well then I want to go home,

One of our two Afro-Caribbean respondents took a very different view, Thus, Mr Green said "if anyone could wave a magic wand I would go back to Barbados" although he also said that "I hate to admit it, but think I have had a better life (here) than in Barbados",

The meaning of independence

Nearly all our respondents stressed their desire to be as independent as possible, Typical of such determination was Mr Hadley who continued to visit his sister via a 300 mile rail journey, despite his blindness of the last nine years, A number of themes emerged relating to how older people thought about their desire to remain independent, As we have seen, many of their comments related to the importance of their homes as the site where they could express their individuality and their need to retain their sense of autonomy and control over their lives, Avoiding illness was stressed by many, as was the need to retain financial independence so that one did not have to 'beg' for help, Both of these points relate to three key themes which emerged, namely the importance of activities and social networks outside the home; the importance of routine; and the strong desire to avoid becoming dependent upon others, Each of these will now be dealt with in turn,

Varied lifestyles outside the home

Although this research confirmed previous studies in stressing the importance of home to older people, we were also struck by the varied lifestyles and interests of many of our respondents, This included someone active in pensioner politics (Mrs Bown), two painters (Mrs Johnson and Mrs Grant), a sequence dancer (Mr Wilson), a theatre group (Mrs Marsh), a philosophical society (Miss Miller) and numerous long haul travellers, often to relatives living abroad, This was in addition to those engaged in more 'traditional' activities such as day centres, elderly person's clubs and church going,

For some these activities seemed more the centre of their lives than their houses, Self esteem and enthusiasm for life came from involvement in these activities rather than from emersion in the home, This point of view was strongly put by Mrs Shaw who is involved in Pensioner's Voice and two older people's forums:

Yes, I've always been interested in politics, one way or another but if I didn't have this interest... I would die, really because I can't afford to go to the theatre which I love, I can't afford to do lots of things - well, this doesn't cost me anything except a few pounds a year membership you know, and I find if you keep yourself mentally well you don't become mentally ill",

Reasons for a lack of home centreness varied, For example, Mrs Grant had always painted but her present intense focus on this activity seemed linked to the recent death of her husband, Others such as the second artist Mrs Johnson gave the impression of someone who was not particularly home centred, Her house was appreciated, but partly because of its convenience for the buses which would take her to her painting and arts clubs,

The pursuit of these activities and interests was usually dependent upon access to transport, either buses, their own cars or lifts from friends, This will be picked up in later chapters since the cost of keeping cars on the road, the reduced frequency of bus services and the inability of most buses to cope with disabled people were major concerns,

Five our households had a car and one Mr Wilson was desperate to regain his licence after his stroke, We live in a car orientated society and it is only natural that our respondents should reflect this, Cars were seen as facilitating independence by getting people to cherished activities or they were valued in their own right, Mr Wilson had worked as a chauffeur and driver, and so it was natural for him to want to remain mobile, Mr and Mrs Booth used the car to travel around local villages where they would stop for pub lunches, Even some of those without cars such as Mrs Grant commented on how an important pleasure with children was often being taken in the car to do the shopping or to go for a drive,

Maintaining a routine

In stressing the rich and varied lives of our respondents, there is a danger of romanticising later life, As already indicated, involvement in activities outside the home was for some a way of coping with the loss of a partner, More generally, we were struck by how respondents stressed to us time and again the importance of structuring their day through routines, This involved not only outside interests and hobbies, but also more mundane activities such as a regular routine for shopping, the laundry, house cleaning, visiting friends and receiving friends, For some keeping active within such a routine was a necessity if reasonable health was to be maintained, Thus, Mrs Higgins explained how she had had two hip replacements and now suffered from rheumatism, It was important that she stayed active and on the move, because if she didn't she would stiffen up and eventually be confined to a wheelchair, For others, certain routines were an enjoyable way to use time, but also an expression of independence, Thus, Mr and Mrs Jones would take bus trips out not only to the park in the summer, but also to their favourite butcher three miles away from their sheltered flat, After buying their meat, they would go to their favourite cafe across the road for lunch, and Mr Jones explained that "this sort of thing is independence to us" because we don't have to ... ask anyone (for help)",

Finally, it was clear that routine represented a coping mechanism for some, and especially for those who were most lonely, Mrs Goldberg explained how she had nearly died during the previous winter, She had felt lonely ever since the death of her husband over ten years ago, and these feelings became intensified when she developed flu and stopped looking after herself, This winter she had been determined to develop a routine which would enable her to retain her independence and to ward off loneliness, This has involved regular contact with friends, regular visits to a local friendly shopkeeper and paying for a helper to enable her to sort through her belongings prior to a hoped for move to a private sheltered flat, The need to structure time in this way had also very much included Christmas:

This Christmas, because last Christmas was so desperate I invited somebody every day, Different people... and I gave them a meal, and it was very nice, but if I had not made this sort of determined effort I couldn't have stood the loneliness, Christmas is the worst time of the year,

The theme of 'making an effort' and 'making the best of things' appeared in conversations time and again with those who had lost close partners or friends and with those whose health was very poor.

Linked to this, it is important not to give the impression that such routines were static, They have to be adapted, amended and sometimes completely abandoned in favour of new routines as circumstances change, Thus, poverty, ill health or death of a partner may mean the loss of use of the motor car so that a regular walk around the village or the neighbourhood has to replace a drive around the countryside or to the nearest town, For those with severe health problems, routines become focused much more upon the home, Some find these adjustments easier than others with Mr Wilson explaining that he liked going to the day hospital after his stroke because it helped to structure his whole day,

Avoiding dependence on others

The majority of respondents left us in no doubt that a major factor in their determination 'to make an effort' was their desire to avoid becoming dependent upon family, friends or the statutory services, The fierce determination of some to remain independent of almost any help was very striking with one couple going so far as to say they "didn't want to go on their knees to anyone especially their children", Miss Mills was 93 and had been still carrying out light secretarial work up to the age of 86, She has both glaucoma and angina, She had a home help once a week, but apart from this looked after herself almost completely, She did most of her shopping (with a little back up from the home help), all her cooking and went out everyday so that her main support concern was the need for a more reliable local authority transport service in the evening so that she could get to her Philosophical Society on time, So for Miss Mills being independent "really means being able to live as I wish to live and not to have to ask for help unless I really need it",

A minority of respondents were reluctant to receive help from the statutory services even when they admitted they really needed to seek additional help, For example, Mr Smith who cared for his wife with Huntingdon's Chorea had been told three years ago by her consultant that he needed more support from health and social services, A social worker had visited but Mr Smith had never really followed this up, He admitted he was "a bit fussy" and felt too many social workers and others were attracted to what they saw "as a good job" rather than because they were committed to helping others, However, whilst the vast majority of respondents were positive about the services they had received, they were still keen to keep their independence on services down to a minimum,

Such attitudes were even more powerful with regard to children and other relatives, Most respondents drew great pleasure from their contacts with children (both direct visits and through the telephone) and many expressed great pride in their achievements, For those living nearby, help with shopping, some cleaning and perhaps the laundry was acceptable, but there was a desire to minimise the demands made (see next chapter), 'Excessive' demands were seen as infringing the independence of their children, while 'giving in' to offers of help was seen as potentially undermining their own independence, Thus, one reason Mr Collins decided to move into sheltered housing was that he was having to ask his son to do more and more around the house and "it wasn't fair to him really", One reason for feeling this way was the work pressures upon his son whose firm was trying to increase working hours while reducing the overall labour force, For others, the concern was the need to avoid intruding upon privacy, Thus, Mrs Martin explained how she had stayed with her daughter and son-in-law over Christmas, and for a further week during the worst of the winter, but she worried enormously that she was "interfering" too much with their lives, This was even though the son-in-law was very good and thoughtful, and had rung her the other night to check how she was with a friendly 'warning' that I'll have you back down here if its snowing, I'll have you back down here at half past nine", Mr and Mrs Harrison had rejected the offer from both their sons of moving to a granny flat because "one son will be in the army until ... he's 50 and the other has got to make his way",

One way of reducing feelings of undermined independence was through stressing the reciprocal nature of any help received, In many families, support for parents is clearly seen by children as returning help which had gone the other way in previous years, This issue is explored in greater depth in the next chapter,

Case Study

Mrs Allen

Mrs Irene Allen lives in the house she and her husband bought on the outskirts of a midlands city nearly 40 years ago, Irene has lived alone since her husband died about 14 years ago and she is now 79, They had four children two of which live nearby, another lives in Norwich and the fourth in Canada,

Until quite recently, Irene enjoyed a very active life, her love was walking, and she belonged to the ramblers club where she made a number of friends, However since arthritis set in about two or three years ago, mainly in her hip, she has stopped walking and become less physically active,



A hip replacement is not appropriate for Irene, as she has to build up her bones, she therefore tries to get out every day for exercise, Despite this setback, she has been able to maintain her second great interest which is painting, She feel such interests are they key to her continued independence, *"I do think its important to have interests, its no good getting to a state of stagnation as you get older, You have got to have an active mind and be outgoing,"* She attends a painting group, which involves the considerable effort of catching three different buses each way, Irene also belongs to a painting society, Whilst out rambling some years ago friend commented on her observance of colour and detail *"you've got the painters eye"*, Her work is of such a high standard that she has recently won an amateur art society national award for her work,

In general Irene is reluctant to ask for help, and she is just able to manage all her household chores, She has a fear of being a burden to others, Her daughter helps with shopping, especially large items, and friends provide companionship, Irene keeps active both physically and mentally, she has a strong social conscience, and always looks forward, Her friends are important, many have the same interests which adds to the richness of her life, She feels she has been very lucky and tries not to worry about the future or dwell on her problems *"you should concentrate on enjoying the now, and not dwell on problems that may crop up later on"*,

CHAPTER FOUR: Receiving support From others

Introduction

The last chapter stressed the reluctance of our respondents to become dependent upon support from others. However, many were in need of assistance and this chapter begins by reporting on the informal support received by our respondents from family, friends and neighbours, and goes on to consider the level and type of formal support received from both health and social services and from the independent sector. The chapter also includes a discussion of how the people felt about receiving support.

Support from family and friends

The majority of those interviewed had of least one, and sometimes more than one family member giving them support. Since we did not interview relatives, there is no means of ascertaining how willingly they provided this assistance. We are also aware that if any of the older people were critical of the amount of support which they received, they would be unlikely to voice that opinion during the interview. For example, Mrs Shaw had not seen her son, who lived an hour's drive away, for two years. Her only comment was that he was extremely busy setting up a new business.

However, the interviews confirmed the importance of the family in providing advice and support, whether it be practical, material or emotional. Many children were involved in doing the housework, shopping and laundry for an elderly parent on a weekly basis. Mr Price's daughter did all these tasks for him on top of a full-time job. His grandson lived in the top half of his house but was rarely around and did not help much when he was. The previous chapter mentioned the regular visits of the son and daughter-in-law of Mrs James. They made their round trip of over 80 miles at least every fortnight, and sometimes weekly, to do things like put up curtains and take her shopping. At the time that the interview took place, they were on holiday and Mrs James's great-niece who lived three hours drive away was going to visit to make sure that she was alright. It was also clear that despite a full life and living some distance away Mrs Grant's daughter managed to support her mother.

She's fairly busy, she's got three teenage children and she's a nurse and she's got a husband who works most peculiar shifts. But she comes over and takes me shopping and sometimes we go out for a ride and a meal together. Sometimes if she's feeling energetic she helps in the house,

Earlier, it was explained how a factor in Mr Collins moving into residential care was the desire to place less pressure on one of his sons. However, he continued to get support from his children. He met one son by arrangement two or three times a week in the park since both had dogs. His other son provided the sort of practical help at the weekend such as cleaning windows which Mr Collins felt that his other son could not do because of having to work long hours.

Families were also important in providing help for one-off items which formal services are rarely set up to do. For example, Mr Johnson's family were able to shop around and find out the best value freezer for her, something which she would have been unable to do because of her mobility problems. Similarly Mrs Shaw's daughter had taken her to visit a number of flats in sheltered housing when she had been thinking of moving.

Support received from family and friends tended to increase when health deteriorated, It was noticeable that several of our respondents had gone to stay with relatives when recovering from illness and how often children would come to stay on a temporary basis when parents were ill, Such arrangements had been true for Mrs Young and Mr &, Mrs Green while Mrs Hall remarked that:

But, if anybody wants to come, we can manage to put them up in that other room, can't we? If we're ill anytime, through the night, our youngest daughter - she's training to be a nurse, she comes and sleeps if we're a bit off colour,

Virtually everyone we interviewed had a living relative but some people's relatives lived so far away that they could be of little practice day to day help, This made Mrs Higgins, in particular, feel lonely, especially as she had a niece who had lived in the same town but had recently moved away,

... I've got no relatives around me, yes I do, sort of feel I'm on my own, sort of thing, So I'm now going to pay for my funeral

Arranging and paying for her own funeral did not upset Mrs Higgins, Indeed she was quite cheerful about it and seemed relieved that her nieces would have less to sort out when she died, She felt "well I just feel that's not a problem for when I'm gone",

Mr and Mrs Booth's circumstances were more favourable in that they had two children, although their daughter lived two hundred miles away and their son lived in Canada, However, they were in regular contact with both children and being at the end of a telephone, and occasional visiting was a source of great comfort, Their son had paid for them to visit Canada twice and had indeed invited them to move there, They were also still able to travel by train to visit their daughter, The lack of day to day family contact was mitigated by the fact that the Booths had few support needs, that their mobility was good and they lived in a village characterised by mutual support,

Relations with children were not always positive, Both Mrs Lambert and Mrs Shaw had estranged relations with one of their children, Mrs Shaw had moved city to help her son out with his business but he had moved away soon afterwards and she had not seen him for two years, The only contact Mrs Lambert had with one of her daughters, who lived nearby, was by phone, Both luckily had other people who were willing to help, However, Mrs Shaw needed a substantial amount of practical support and could only call upon one daughter who lived some distance away, The previous chapter stressed the desire of our respondents not to be a burden on children - however it is possible some were trying to make the best of a difficult situation,

Feelings about receiving help from the family

With one or two exceptions people did ask their family for help when they needed it, although many people found this difficult to do, We have seen how fear of becoming a burden or becoming dependent on family members was expressed by many people interviewed, Several were keenly aware that their sons or daughters had busy lives, Some mentioned increasing pressure at work, others the fact that their children had their own lives to live, or that they were already doing a lot, During the snow, Mr Collins had waited for his son to ask if he wanted his path cleared of snow rather than ask him, and he commented:

... to even ask my sons to do something, I don't really like to do that because I believe they've got their own lives to live, you know, they're really putting themselves out to do these things for me ...,

Mrs Johnson commented in a **similar** vein:

Well, the shopping is a worry at times, this is the problem, I am not supposed to carry much weight,, There are so many things I want done, I don't like to bother my daughter too much as she helps me so much already,

Some respondents **reflected** upon the fact that wanting to be independent whilst not being a burden to others had a high price, Mrs Shaw said that she was sometimes inclined to say that she did not need help when she did because of her fierce independence. But she admitted:

Now there is a price to pay for that because although next door don't mind putting a light in, I don't like imposing too much, it's not fair and we elderly people are awkward to help because we are independent on one hand and we need help on the other,

All these factors made a number of people disinclined to ask for help or uncomfortable about doing so, There was no suggestion from those interviewed that their children were making them feel uncomfortable although that may indeed have been so in some cases, There were others who seemed to find it easier to accept their children's support, For a few people this seemed related to the fact that relatives had made it very clear that they wanted help, Mrs James had told her son she did not know how to repay him **for** paying for her fare to visit Australia on a regular basis, His reply was that it was he who needed **to** repay her for all that she had done for him, Similarly, Mrs Lambert was happy to receive help from her nephew because he had made it **clear** that **he** too was repaying her **for** when she had helped to bring him up after his father's death,

Other formal sources of support: friends and neighbours

It is hardly surprising that friends and good neighbours were an important part of the lives of many of the people we interviewed, both in terms of maintaining independence, and in terms of providing support and companionship, Mrs White said:

I think that is very essential, health and friends I think are the most important two things as long as you have each other of course,

Friends were especially important to Mrs Jordan, who was blind, housebound and had reduced hearing, Mrs Martin's neighbour was so helpful and their relationship so close that she considered her like a daughter, They had known each other for over 60 years, Mrs Young still lived in the house in which she had **been** born and had seen the area change from a predominantly white one to one "where Asian and Afro-Caribbean people also lived", Her next door neighbour who was Asian regularly cooked her meals, Mrs Young also had a large number of friends, Several people had friends who could give them lifts such as to the GP, to church, to activity clubs, regular shopping, or to events such **as** the theatre, Mr Hadley, who was blind, said of his friends:

Usually friends are very good, They usually say, 'We're going to X' or 'We're going to Y', 'would you like to come?'... I have a good friend who comes every week and we go for a walk ,, I go to church with a neighbour every Sunday,

Mr Hadley was also taken by a friend to the local golf club to play dominoes every week. Mrs Morris said that she depended on her friends and that she felt wanted and needed by them, A network of mutual support had developed in the village where she had lived for the last 20 years, She provided services like baby-sitting and other people helped her when she needed them to, A few other people had similar networks where they were given support but there was an opportunity for them to reciprocate in some way, For example, Mrs Evans shopped for fellow residents in her sheltered housing for rent scheme, but more recently others had shopped for her (especially for her cigarettes) as a result of her great fear of having a fall in the recent snowfall, After his interview Mr Wilson was going to visit his best friend who was convalescing after a major operation and it was this friend who had to do most to encourage him not to give up after the death of his wife and his own stroke, For Mrs Shaw who was fiercely independent, opportunities to reciprocate and be of use to her next door neighbours by baby-sitting for their children was no longer possible as her physical condition had deteriorated, For some people, the experience of becoming less mobile and more housebound was compounded by their inability to meet friends, or friends' inability to get to them, In some cases friends had recently died,

Another lifeline for many people was keeping in touch with friends, and indeed relatives by telephone, Being there for someone, even if not in person was also important, Mr Green had a close friend who could not easily visit because of his caring responsibilities, However, his friend's offer that he should feel free to ring him at any time of the day or night if he needed to was much appreciated,

Mrs Marsh said that it was the visits from her friends after she had moved into sheltered housing which made her feel that she had succeeded in creating a home for herself:

I think once you start having visitors, you feel as though you've still got the same people, and I think really and truly.. I think it's got a lot to do with it really,

Several of the people in sheltered housing derived enjoyment from their relationships with other residents and/or the social activities commonly provided in sheltered housing such as coffee mornings or bingo, For Mrs Higgins, however, activities had tailed off because some of her fellow residents had died, and new residents weren't as keen to get involved, As a result, she and a couple of other residents organised an informal get together over a cup of tea in the communal lounge two or three times a week,

Another area of support was neighbours and local figures like vicars, doctors and shopkeepers, Mrs Shaw's next door neighbours would change a lightbulb for her and occasionally ask if she wanted anything from the local shops or a letter posting, Other neighbours would do the same, However, sometimes several people would ask on a day when she needed nothing and no-one would ask on a day when she needed a favour doing, This meant that occasionally she had to stand at her front door hoping that a neighbour of whom she felt able to ask for help would go by,

Examples of helpful local services were Mr and Mrs Jones's chemist who would arrange for their medication to be delivered to the sheltered housing complex, Mr and Mrs Booth's GP had found a local person to drive them to the nearest town to do their shopping on a weekly basis, They considered the £4 they had to pay very reasonable, Mr Green's vicar would give him lifts to church from time to time and also visited quite regularly for a cup of tea, Mrs Goldberg also derived some support from a local shopkeeper and priest,

The importance of reciprocity rather than just being on the receiving end of others' kindness and support also became clear during interviews. Both Mrs Shaw and Mrs James had children who regularly travelled some distance to help them with shopping and general household tasks. Both women felt a lot better about this because they were able to pay the petrol money out of their benefits. Mrs Morris said that she felt wanted and needed by her friends. Similarly reciprocity was a key element in Mrs James's and Lambert's relatives saying that their attentions were a way of repaying support they had received as children. They may have made it easier for the help to be accepted. Being able to reciprocate is of central importance to social relations in our society. The person who takes but gives nothing is universally criticised. Many older people share such cultural views and it is therefore hardly surprising that many of them find it hard to accept help.

Statutory and independent sector support

A number of people interviewed received services from the statutory or independent sector. Whilst a small number of respondents were receiving an intensive range of services, a more common picture was of people receiving a low level of service with the most common services being home care and day care. One reason for this is probably the fact that many of the people we interviewed did not appear to have high dependency needs. In terms of how people evaluated their services, most seemed pleased and grateful to be receiving a service. However, Mrs Martin's comment may go some way to explaining a lack of criticism:

...they don't do it like you would do it for yourself you know, they haven't the time ,, I mean I couldn't do it in the time they are allowed ,, you haven't to say anything because you are dependent on them and they are very obliging like if I want a letter posted or anything they'll do it,

This suggests that a mixture of gratitude and concern about the consequences of criticism may make it hard for some people to express dissatisfaction. Against this, others were unambiguously positive such as Miss Mills:

,,I have a home help who comes once a week and its for an hour and she does the hoovering and the floors, the things that I can't do you know, And that's really quite adequate at the moment,, and actually I believe, you know, if you need more help, if you need her to give hours you can,

However several people were critical about the adequacy of the home care service. The two main criticisms were that the service was insufficiently flexible and that it did not offer people enough hours. Mrs Clark asked the question:

... what good are home helps?... Half an hour two mornings and an hour another morning, I've got someone lined up if I want to pay them privately, but it all costs a lot of money,

She had ended up doing much of her own housework, including hoovering, albeit with some difficulty since **she** could only walk by using a walking stick in each hand. Mrs James had also decided not to have home care, although the warden in her sheltered housing complex was keen for her to do so. She gave the reason as the fact that they that would not clean windows nor clean higher than an arm's length reach,

When Mr Collins moved to sheltered housing, the number of hours home care reduced, as did the quality of the service that he was used to, He contrasted the situation when living in his own home:

..they home help came and did all my housework, ironing, and she was very good, she never asked what was to be done, she used to do it... I mean she'd even come in and you'd hear her mess about in the kitchen, you'd say what you doing, oh she'd say I'm making you an egg custard you know ,,

and since moving:

..they just want to nip in and fetch your shopping and that, it took one or two arguments and that, but they eventually worked around to somebody permanent,

In other words, the service he was given was more restricted than what he was used to, Indeed, several people said that they were no longer able to keep their home to the same standard as they were used to,

There were other examples of social services trying to reduce levels of service and costs, For example, the rental of Mr Hadley's telephone line had been paid for by the Social Services Department since he was blind and classed as an essential user, He received a visit from a social worker saying that the Department wanted him to take over payment, Luckily for him his suggested compromise of paying half the fee was accepted, Mr Hadley also spoke of the day centre he attended having to become self-financing and how the fee for lunch was steadily increasing, Mr and Mrs Wallace spoke of how their home care received from social services had been cut back, They found this unsatisfactory and had started to use private home care organised by Anchor who ran their retirement housing scheme,

Others complained about the rigidity and unreliability of services, Thus, Mrs Shaw disliked how meals on wheels "all taste the same" while Miss Ashman, Mrs Clark and Mr Green all complained about the unreliability of transport to day centres and hospitals,

In contrast, the help which Mrs Marsh received was flexible because she paid for it privately:

..a lady that I've known for about 15 years, she comes in once a week on a Monday and she cleans everything, She comes in at 9 and she stays until she has finished the whole flat... and I've got another lady ... it's looking after me doing personal things ... I mean I can't clean shoes and you'd be surprised at the little things you can't do, sewing on buttons and that sort of thing ,, and maybe she prepares some food for me, or something else I can't do,

Mr Hadley had also established private help for himself after finding the range of what the local home care services would do for him too restrictive, He had the financial wherewithal to opt out of the statutory services and to buy a tailor-made service, This included a housekeeper who came every morning for three hours to cook, clean, iron and garden and who then returned every evening to eat with him,

Getting advice about services

Older people often have a variety of requirement for advice relating to health matters, accessing statutory support or assistance with financial or benefit queries, We therefore asked people who they would turn to if they needed advice about such matters, Many people said that they would ask their families or a local organisation which they had already used and found helpful, such as Age Concern, Care and Repair or Anchor services such as Staying Put or Moving On, Several people in one of the study areas said that they would contact the local authority neighbourhood office, which was a resource point for accessing advice and information,

However, some people were very confused about where to seek advice, We asked everyone whether there were any gaps in the services received, and several people said that they did not know what services they could or should be receiving, Correspondingly they felt unable to really comment and the following remark by Mr Price was quite typical:

..I don't know that support I should get,

Mr Hadley commented:

..the trouble is you don't know what there is do you, since nobody ever tells you,

Surprisingly, people in this position of uncertainty about where to seek advice about service entitlement included Mrs Shaw, who was a member of Pensioner's Voice and active in older people's forums,

Service gaps

Many of the people interviewed that had impaired mobility felt the lack of services which were flexible and specific to themselves, Mr Finch would have liked someone to make his bed, Mr Price would have liked help with cooking and Mrs Shaw would have loved to be able to take a bath but felt unsafe having one on her own, She had found the service response disappointing, There was no bathing scheme in her area, By contrast, Mr Finch, who lived in another area, could use an Age Concern bathing scheme, Mrs Shaw was instead offered the chance to have a bath in a residential home at the cost of £5, plus the cost of a taxi there and back, one of which she could not afford, She was also offered the choice of having her bathroom substantially altered, which she did not want,

Mrs White, who cared for a husband disabled by a road accident hinted that she need respite from her husband, She said that she had not had a break for two years and that there had been no follow up from the hospital or GP, Her comments suggest that she would have been placed to have been offered support but had not asked for it:

The support has been very poor, the doctor never comes to see him unless he is ill, I haven't had any help from Social Services but I haven't asked for it because I am rather independent,

The interviews took place during the winter months and it was clear that snowfalls made many people unable or unwilling to venture out of their homes, Many people were dependent upon the thoughtfulness of friends, neighbours or relatives to clear their paths for them, No-one even described this situation as a service gap, However, it could be described as such for those people unfortunate enough to have no-one available or willing to help,

The examples of dissatisfaction with meals on wheels and home care services previously mentioned also highlight service gaps since the required service was not available, Other people mentioned that they were unable to maintain the standards of household cleanliness which they were used to, Again this was not always described as a service gap, For those not receiving statutory services, this may have been due to lack of availability, eligibility or awareness of services, It may also have reflected worries about possible charges,

Another issue which emerged from the interviews is that **many people needed** help with the myriad of small, often taken for granted tasks, Such tasks may not even be considered as important until you find you can't do them yourself, yet their contribution to well-being and self-esteem should not be under-estimated, For example, having a bath, having a bed made, having shoes polished having buttons sewn on, replacing a lightbulb (especially important for **those** people who **have** poor eyesight), Miss Mills and Mrs Shaw also **spoke** about the importance of being able to do your own shopping and choose your own food rather than have someone else do it, Miss Mills remarked:

I've realised that when someone shops for you, you've got to be very careful to be very explicit about what you want, because they always bring, almost always something that really is not what you want, And this is an important thing really in a way,

Home care staff from the statutory services tend to shop for people rather than take them to the shops, This is hardly surprising given that they are so hard-pressed, However, this may not necessarily be what people would want if they are given the choice, Yet **using** a private sector home care service is likely to prove costly,

Does support help or hinder independence

We asked people whether the support which they received helped or hindered **them** in maintaining their independence, People generally found **it** helpful despite the detailed complaints just listed, Mrs Shaw was one of the few people who remarked upon the way in which receiving support sometimes made her feel that professionals were trying to take over or thought that they knew best, She commented about her bath problem:

„but I don't want people coming and pulling my house to pieces to get some facility when I can see another way of doing it, but can't often explain how I feel, Now that sounds awfully ungrateful, People are coming, you get the physiotherapist they come in to help you, but don't tell me what I want, let me tell you,

Mrs Shaw also gave an example **of** professional kindness which **she** did not find helpful, She had been unable to keep an appointment to visit a centre where a range of mobility **aids** were displayed, The physiotherapist had rung **to** say that **she** would call round instead to make an appointment in all probability because she thought that she was making life easier for Mrs Shaw, However, Mrs Shaw wanted to see the variety of aids **available** for **herself** but was wary of saying this to the physiotherapist in case **she** **seemed** ungrateful,



Case Study

Mrs Cressy

Mrs Gwen Cressy has lived in local authority sheltered housing for 5 years, having previously lived in a semi-detached house, For the first three years she lived there with her husband who suffered from Alzheimer's disease, but as his health deteriorated he moved into a nursing home until he died last year, Mr and Mrs Cressy had always been active, both worked all their married life, and even in retirement had part time jobs, The move into sheltered housing was prompted by her husband's deteriorating condition, but also because her arthritis made using the stairs very difficult and she feared falling, The garden in their previous home had been beautifully tended over the years yet had become neglected and so was also a worry to both Mr and Mrs Cressy,

Gwen has had two hip replacements, one of which was unsuccessful, As a result she is unable to stand or sit still for too long as she becomes very stiff and her back aches, This is a major a problem at night because it means she has to get up and walk around, Gwen has no children and her niece, who used to live locally, has now moved away to the north of England, Friends and neighbours help her out, but the majority of help she receives comes from social services and voluntary organisations, Gwen likes to get out once or twice a week to buy some local shopping, *"Its as far as I can go, and then I have to sit down on the stool in the little shop, but I do like to go out if I can"*, She also does the light chores around the house, but home care services come twice a week to do the vacuuming, the main shopping and collect her pension, In addition Gwen has meals on wheels three days a week and attends the Arthritis Club once a month, The other service which is a great help is Dial a Ride which she uses once or twice a month, After her hip operation, social services offered to convert her bath to a shower, which was something Gwen had tried unsuccessfully to obtain for her husband,

The move to sheltered housing has been very successful for Gwen, She is glad to have the security of the warden service as she feels she is on her own since her husband died, She also feels she receives more understanding and help here than she would have done on her previous housing estate where many of her neighbours were younger and out at work, Gwen would have felt a nuisance to them, *"You all understand each other here, if you have difficulty moving around the others are more sympathetic because they know how you feel"*,

CHAPTER FIVE: Housing issues in later life

Introduction

This chapter focuses down upon housing issues in later life, We have already discussed the attitudes to home of our respondents and how this relates to their present accommodation, This is now explored in terms of more detailed issues such as what they liked and disliked about their present housing, and how this related to whether or not they were thinking of moving home,

Comments on likes and dislikes were very varied, As we have already seen, some felt an attachment to their houses because of the length of time they had lived there, Others stressed particular features of their house which they particularly liked, These included a central fire place (see the case study at the end of this chapter), the garden (Mr Finch), the general warmth and compactness (Mr and Mrs Booth), the quietness of the cul de sac (Mr and Mrs Hall), the sense of security (Mrs James), good neighbours (Mrs Saunders), and the closeness of local facilities or transport (Mrs Johnson),

Mrs Martin stressed the importance of the stimulating view from her front window which was of a wonderful Lake District valley, It might have been thought that she would express great annoyance at the motorway running through the valley, but this was not the case,

Interviewer: What did you think when the motorway was first built, did that break your heart,

Mrs (Martin): Well, everybody was against it but oh, I wouldn't like to be without it, oh no,

Interviewer: You get used to it?

Mrs (Martin): It is something to watch... (the) traffic ... all comes this way for the lakes like,

Mrs Grant was interesting in that she listed her garden as a like and dislike, Hence, she loved to sit in it during the summer, Yet its upkeep was becoming a major concern because her health was not good enough to allow her to do all the work herself,

Certainly, as circumstances changed, so our respondents had been forced to re-evaluate the strengths and weaknesses of their present accommodation, Bereavement, for example can spark off concern about loneliness, personal safety or house maintenance (Mrs Goldberg), Ill health can generate concerns about the ability to manage the home, For example, some had worries about the maintenance of the garden (Mr Collins and Mr and Mrs Jones) or managing the stairs (Mrs Marsh and Mrs Higgins), In some cases, such factors had resulted in decisions to move to sheltered accommodation,

Dislikes about accommodation were equally varied, These included troubles with stairs and garden as already mentioned, poor heating (Mr and Mrs Smith), excessive size (Mr Price), worries about personal safety (Mrs Young), home maintenance concerns (see next section), and so on, Personal safety was a major worry to the majority of respondents living in the urban rather than market town or village settings, Some of the latter did not even bother to lock their doors during the day, an attitude in marked contrast to the approach of Mrs Shaw, Mrs Shaw described her house as "like Fort Knox", a response to the fact that she has been robbed five times, including being mugged outside her door and having her home ransacked when she answered the door thinking that her grandson was calling, Mrs Young had also been mugged on her way home when a "fellow came at the back of me and just took my bag", Her elderly neighbours who would open their door to any stranger, had been burgled on six occasions, Mrs Young had so far avoided a burglary herself

because she was much more careful, and had the back up of good window and door locks, Such experiences left her feeling very ambivalent, She felt safe in her familiar home yet:

... I do get a bit frightened but not very often, If I'm sitting here at night and start thinking about things, I get a bit frightened but it passes, But it's only the area, you know, you read such terrible things around here that it does make you a bit wary like

Home maintenance, home improvement and home adaptation

Home maintenance, improvement and adaptation issues were prominent concerns among our respondents, Although this was partly a reflection of how the sample was drawn (see Appendix), the research did underline again how a failure to resolve these issues can undermine the quality of life of older people, and sometimes result in their deciding to move, Sometimes concerns were about home maintenance, such as Mr Price remarking :

You see this house is extremely large and there is no way that she and I can maintain it as we used to, There are two flights of stairs - i hardly ever go up there - it's a hard slog,

On other occasions, more substantial home improvement work was the central worry, Mr and Mrs (Bell) had had two serious house floods which sparked off major damp problems, In the end, a massive home improvement package had to be carried out involving a new ground floor being laid (the old one was concrete), a new damp proof, rewiring and re-plastering,

Typical of those with home adaptation concerns were Mr and Mrs Murphy (see case study at the end of chapter six), Both these council tenants were diabetic and suffered from arthritis, Mrs Murphy had angina and Mr Murphy has to use crutches because of a road accident when working as lorry driver, Neither could manage the stairs of their council house and so had considered flats and bungalows but none of these were near their present home where they had lived for nearly 40 years, and which was close to the houses of three of their children, As a result, the housing department and social services were persuaded to fund a ramp, a lift from the sitting room to the spare bedroom and a number of other home adaptations and improvements so that Mr and Mrs Murphy could stay put,

Older people often find making such major housing decisions highly stressful, Eleven of our sample had received help from home improvement agencies such as Anchor Staying Put projects in coming to a decision about whether and how to organise home maintenance, improvement or adaptation work, A great deal of gratitude was expressed for the availability of this advice and support, The vetting of builders (Mrs Shaw), knowledge of how to finance work (Mrs Grant), technical knowledge of building work (Mr Bell) and approachability (Mr Price and Mrs Clark) were all mentioned by respondents as reasons why they had such high opinions of project staff,

The case study of Mrs Monksteel at the end of this chapter illustrates how the lives of some people were transformed by the work carried out, However, major home improvement and adaptation work is expensive and disruption during the work can be very stressful, Some respondents who had taken out loans from building societies and banks to help fund such work felt an element of their financial independence had been lost, with Mr Green complaining of how his house deeds were now with the bank because of the loan taken out, Mrs Grant remarked on the stress of having to leave her cottage during the period of major building work while Mrs Lambert was interviewed in her house when the builders were in:

It was originally to take five weeks, this part of the work, but now it's going to take another three weeks to a month, So I am in this state, They are very good, they are very pleasant but I did ask them to put the skip in further because it is a trouble to get in and out of the house, I normally lived in the room which they are bringing everything through because there is no way round the house ,, When it's all done, I am hoping it will be very nice,

But once again we were struck by the variety of responses received with Mr Bell, a former highways maintenance worker saying how fascinating he had found the opportunity to observe the building work being carried out in his house,

Making housing decisions

Our colleague, Frances Heywood, has developed a housing options appraisal method called Hoamchoice (1994) which is based upon a belief that owners and tenants assess their houses by a number of criteria, such as size, location, comfort, cost, condition and control. Thus, an elderly couple might be delighted with the location, cost and size of their owner occupied house, but may have lost their sense of control and comfort because of its deteriorating condition. Such a situation may spark a decision to consider whether the best option is to try and improve the property, to move on somewhere else, or to struggle on as they are,

We feel our research findings suggest this is a very helpful type of approach for understanding the 'push' and 'pull' factors facing people. In terms of our own sample, we were struck by how someone like Mrs Young had reservations about the location of her house in terms of personal safety, but that she had no intention of moving because of her liking for other aspects of the house, including the location of the house in terms of neighbours. Her family had put her under pressure to move because of the local crime, but she had decided to stay because "it's better the devil you know",

Some of our respondents felt that they had missed the chance to move and that they now regretted this. Thus Mrs Martin wished she had moved to the same town as her daughter twenty years ago. Now, she felt too old to cope with moving into a new place of her own while she did not wish to impinge upon the privacy of her daughter and son-in-law by moving in with them. Mrs Johnson had nearly moved to a newly built two bedroomed house which was close to her daughter but the deal fell through. The subsequent collapse in house prices combined with her need to carry out home improvement work means that she feels moving is no longer a realistic option,

Deciding whether or not to move can be as distressing and worrying as deciding whether or not to improve your house. Four of the households from the midlands case study had received advice from an Anchor 'Moving On' Project. Two of these households had moved into private retirement housing and one hoped to in the near future. Advice received was appreciated in terms of both how to finance such a move (Mr and Mrs White) but also more generally in terms of clarifying potential options. Mrs Goldberg explained how her first experience of asking about sheltered housing had been disastrous:

The first place that I found, they didn't (understand this) distinction about renting and buying... and this person said on the 'phone.'... You own your house? I said 'yes', 'Oh, in that case we can't do anything for you! Full stop, And not thinking what it means to that person who is desperate to find somewhere,

It was not until Mrs Goldberg was put in touch with the 'Moving On' Project that she was able to make any progress in terms of exploring her housing options,

However, it is known that the housing options available to older people are often quite limited, especially for low income occupiers who wish to move on (Rolfe et al, 1993b). Mr and Mrs Smith were typical of such individuals. They continued to feel trapped in the council house they had bought. It was no longer suitable for Mrs Smith because of her Huntingdon's Chorea and yet they were unable to find an acceptable alternative due to their house being in negative equity,

Case Study

Mrs Monksteel

Mrs Daphne Monksteel lives in a small cottage in a village on the outskirts of a northern market town, She moved with her husband from Kent nearly 20 years ago after his retirement, Daphne trained quite late as a psychiatric nurse and continued to work for a number of years before she herself retired, Daphne's husband died nearly four years ago and she is now 72 years old, She is extremely happy in her home, and as soon as she moved she felt she really fitted into the area, She adores her cottage with its open fire, which she feels is the heart of her home, she loves the atmosphere of the house, and the tranquillity of the village and its setting, Daphne has four sons but only one lives in the north west, However neighbours in the village are very friendly and help each other out a great deal, For example Daphne babysits for a neighbour who in return helps her out when necessary, Daphne runs a three-wheeler car which she relies heavily on to fetch shopping and to go with friends to church, as there is very little public transport in the area, She hopes to keep the car on the road for as long as possible as it keeps her independent, However she only has a small occupational pension in addition to her state pension, so hopes repair costs will stay low,

Over the years her cottage became run down and eventually fell into disrepair, The flagstone floors caused the sitting room and kitchen to become very damp, The roof leaked and water had begun to pour down the walls, As the cottage deteriorated Daphne considered moving to the nearest town as she did not have enough savings to renovate, Whilst looking at other properties she became extremely despondent and unhappy at the thought of leaving her small cottage, the village and all her friends that she had made over the last 20 years, Her moving choices were limited because of her lack of resources, She would have to go to a very built up area where she would not know anyone, *"To be honest I was getting very anxious, very anxious indeed, I couldn't bear the thought of leaving my beautiful home"*,

The turning point came when she remembered that a friend in a nearby village had told her about the organisation 'Staying Put' and about how they had helped her with her own house repairs, She contacted the agency, who visited with the local environmental health officer, An assessment was made of the house, and application was made for a home improvement grant, Daphne received a full grant because of her low income and savings, The house has now been transformed, There is no longer any damp, the house is heated by the back boiler of the open fire and now keeps much warmer, while the roof is now weatherproof because of the repairs, In addition some new kitchen fittings have been installed, The plaster has now dried out, and recently some friends from the village have started to help her redecorate,



The repairs have made all the difference to Daphne who is now able to fully enjoy her cottage again, In addition her health has improved, Her rheumatism has gone, and she now realises it was caused by the damp, Daphne is delighted at the result, she feels she is very lucky indeed, and overjoyed that she can stay in her own home, *"Talking about it has made me realise, I can't think what would have happened if I hadn't had the house done, I've got a lot to thank-Anchor for"*,

CHAPTER SIX:

Improving the quality of life of older people

Introduction

Many of our respondents views about their worries and concerns about service gaps have already been illustrated, This chapter draws together some of the key themes which emerged, and relates this to the views of those interviewed about their quality of life and how it might be improved,

Quality of life

As one might expect, our respondents had very differing views about their present quality of life, although the views were not a simple reflection of what doctors and other professionals would tend to see as their objective health status, For example, the physical health of Mrs Goldberg appeared much better than most of our respondents, but she stressed "I live from day to day", a reflection of her long-standing problems with loneliness, On the other hand, Mrs Mills, the 93 year old in private sheltered accommodation, described herself as both "very lucky" and "extremely happy" despite her numerous health problems which she saw as inevitable for someone of her age, She reflected that such an attitude:

... depends on your temperament, doesn't it? And I mean one day, one sees the bright side of everything. The next day you get a bit gloomy... I mean it's just life, that's life,

Miss Ashman also indicated that her mood varied from day to day, but now that she was nearly bedbound she felt increasingly that "I've got no quality of life, none at all",

In assessing their quality of life, many of our respondents made allowances for their age and their health problems, Thus, Mrs Lambert, an 83 year old respondent with rheumatism, arthritis and poor eyesight responded to the question about her quality of life in the following way:

I would say for my age very good, I would say I do enjoy what I do, I wake up a lot in the night and I don't like that because I wake up with pain, But I usually bring up things to be able to boil a kettle and I take pain killer tablets and then I can get to sleep again,

Mrs Lambert was also very clear about what would improve her quality of life, namely the installation of central heating, In general, our respondents were well able to articulate both what would most improve their quality of life and their main worries about the future,

Avoiding residential and nursing home care

Respondent after respondent expressed their greatest fear as losing their independence, and ending up in residential or nursing home care with Miss Miller saying that "it would be like going to prison for me", Mrs Harrison said they felt the only consolation about going into a residential home was that "when it happens, probably your mind has gone", but she still worried at the thought that fee payments "could lose all the money that you built up, even though you haven't got a lot", Mrs Ashman stressed that "I think the most important thing is that I stay here, that I don't have to go to a home", Mrs Goldberg had twice spent some time in a residential home first when recuperating from an eye operation and once when recovering from a period of self neglect, Although the second occasion "probably saved my life", she still felt she wished to avoid living in such accommodation on a permanent basis at almost any cost:

I found I couldn't possibly live in a place like that because people just sit there and you are not expected to do anything, and the television is blaring all the time and nobody is listening, And oh, I think...I couldn't live like that and I think if I had to I would probably be just as far gone as the others,

It is important to remember that most of our respondents were basing their views not upon direct experience of residential and nursing home care, and that perhaps part of their worries was that entry to such accommodation would indicate a major deterioration in their physical health, and perhaps, even more worrying, their mental health. Indeed, such provision is increasingly associated with older people with dementia, and several of our respondents went out of their way to stress their own mental alertness and how they maintained this through reading, doing crosswords and their other interests. Mrs Higgins was unusual in that she did see a role for residential homes and she mentioned a 98 year old neighbour who would be "better off" in such care because of her constant falls. But she also remarked that this judgement was partly because "she doesn't know the time and day, and that sort of thing",

Transport and mobility issues

We were struck by the extent to which most of our respondents were determined to retain their interests and social relationships outside of the home. For these people, access to appropriate and affordable transport was critical to the maintenance of a good quality of life. For some, this meant no more than the ability to walk the streets of their neighbourhood without fear of being physically assaulted. The previous chapter illustrated that this was very much not the case for some of our respondents. Even though Mr Wilson said he felt he lived in a fairly safe area, "I wouldn't sort of go out for a walk just for the sake of (it), not after dark anyway",

Many people expressed their dependence either upon the local bus service or upon local authority funded 'dial a ride' schemes. For example, Mrs Saunders said she would not know what to do without her bus pass while Mr Finch expressed his appreciation of his "taxi card" which meant he could take a taxi ride for £1,50. Dissatisfaction with bus services were expressed on two accounts. First, the low frequency of services, especially in rural areas was seen as a major obstacle to retaining independence. Mrs Martin remarked bitterly how all she wanted was a bus service to the market town on a "Monday, Wednesday and Saturday - but we cannot get it". As a result she had become dependent upon her daughter in order to go shopping. The complaints of both Mrs Grant and Mrs Shaw were rather different in that their declining health made it difficult for them to get on and off buses, and it was the failure of bus services to respond to their impairments which risked denying them access to their wider social activities. As Mrs Grant explained:

I'll tell you what makes me very irritable, I can't get on a bus, I can get on a bus when I go out with the art club I'm a member of because they know I'm there and they have a little step which they put down for me, But the initial step on the buses is too high for me, If I could get on them I could go to town on my own which would be nice,

She felt she would be "a prisoner" in the village if it was not for help from her friends and daughter,

Finally, there were those for whom keeping a car on the road was critical to their being able to retain a good quality of life. Mr White was the respondent who had been knocked over by a car resulting in serious leg and head injuries. As Mrs White explained:

I think I am very fortunate that we have a car... Obviously I get attendance allowance for looking after Geoff but all that money has to go on keeping the car going, It's the only way he can get out, It seem unfair,

Indeed 'keeping the car going' was a major concern of several of our respondents, with increased ill health or financial problems being seen as the main threats to achieving this,

Housing concerns

The whole thrust of the community care reforms is about enabling older people to stay in their own homes if that is their wish, This research adds to the growing body of research which suggests the successful implementation of this policy requires adequate mechanisms to respond to housing needs and housing worries, In many instances, it will be possible to resolve house maintenance, improvement and adaptation problems within people's present homes but, where this is not possible, there is still a clear need for older people to receive advice about possible housing alternatives to their present accommodation, It was clear that the quality of life of many older people is undermined by their concerns about their personal safety in terms of burglary and their vulnerability to assault both inside and outside their homes, A failure to address this last point could easily undermine the community care objective of enabling people to 'stay put',

Money matters

Income and resources matter to older people, For the 'better off' in our sample, such as Miss Mills and Mr Finch it meant that activities and interests could continue to be pursued, However, Miss Mills noted that her reduced mobility made her more and more dependent upon taxis which she could not always afford, Indeed, for this group, the main struggle was how to maintain their lifestyle as resources became stretched, Mr and Mrs White worried about the cost of keeping their car on the road since it was central to their social life, while Mrs Grant expressed concern at the impact on her weekly disposable income of the loan repayments for the home improvement work which had been carried out,

Attempts to increase income could be fraught with dangers, The two children of Mr and Mrs Booth were both well established in their careers and supported their parents in joining a home equity scheme, Unfortunately, the type chosen was the now illegal rolled up interest kind, Mr and Mrs Booth had found themselves owing a great deal of money to a building society rather than having their weekly income increased, This had become an enormous source of worry and anxiety to them, with the biggest fear being that the building society would try to reclaim the money and they would have to leave their cottage,

For others, money worries were in terms of a week to week struggle to heat their homes and to maintain some kind of social life, A good illustration of people in this situation was Mr and Mrs Murphy whose situation is written up at the end this chapter, Mrs Lambert has already been quoted for both her positive outlook, and her desire for central heating, but she also remarked that "I just don't have the money to put such heating in", Those dependent on state benefits like Mr and Mrs Murphy sometimes expressed confusion and bewilderment about what they were or were not entitled to claim,

Illness, death and dying

In writing about home and independence in later life there is a need to recognise that home and independence can't always be maintained under all circumstances. We were talking to a group of people, nearly all of whom had lost people close to them in recent years such as partners, other relatives (including children in some cases) and close friends. For many older people, physical illnesses and impairments will get worse rather than better and death for some is usually not that far away. Indeed Mr Collins said that he did not expect things to improve. Not surprisingly therefore, many of our respondents' thoughts sometimes turned to their future. Some people, such as Mrs Hill, said that they lived day to day and chose not to think about the possibility of increasing infirmity, health concerns or approaching death:

because it would worry me no end, I just get on with it, and that's it, best I can, I worry a bit about keeping me health and that sort of thing,

Others voiced fears about their situation deteriorating and others seemed to have found a way to accept whatever the future might hold. However, people's responses were not fixed and varied over time. Mrs Grant took the view that there was little point in worrying about death since "I've reached 73, why take on an added worry". This was said in a very positive way in terms of a determination to continue to find pleasure in life. Mr Finch, aged 80, accepted the closeness of death but worried about the circumstances in which it might happen:

I accept it, I know that I am old, and these pains that I have and that sort of thing, but I just don't want to fall down and sort of knock myself out or kill myself or something. But that has got to come sometime and not too long I should think,

Mr Price, a lay preacher most his adult life, remarked that, "I know one day I have to go" but "I'm expecting it any time, it doesn't bother me." In terms of her health, Miss Mills remarked, "you worry a bit sometimes about your health remaining, but I think I must be fairly optimistic really by nature". In common with Price, the idea of death did not worry her but both worried about being dependent. Two women (Mrs Martin and Mrs Lambert) had made or carried out plans to cope with the possibility of increasing infirmity. Mrs Martin talked about the layout of her home and said: "if the worse came to worse, I could always put a bed in there,," which would mean that she did not have to go upstairs. Mrs Lambert had had a downstairs bathroom built in case she became more infirm. Mrs Harrison was more of a worrier:

you don't like to sort of say, well what's going to happen in the future sort of thing because when it happens, probably your mind's gone,

whilst her husband said:

the thing I fear more than anything is being bedridden, not being able to move,

Couples interviewed often reflected upon the impact of their death upon the one left behind. Thus Mr Smith worried about how his wife, who had Huntingdon's Chorea, if he died first. Equally, Mrs Wallace said that she was "always worried that my husband will die before me", although it was her health which was more problematic because of her angina, high cholesterol and general blood circulation problems. When Mr and Mrs Jones looked to the future, they worried about leaving each other and about also being a burden on their family,

Concerns about future health, dying and residential care also combined in various ways, Mrs Hill said that she always worried that if her husband died first, then she would be turned out of her home and have to go into residential home, Mrs Shaw had told her daughter that she would not go into hospital if she became ill as she was fearful that once there, she would be forced into a home, Mrs Clark had recently had leg ulcers and her account of going into hospital also suggests some fear about the consequences of doing so:

the doctor said two weeks bedrest with my leg at 90 degrees, It took them a month to persuade me, but they cornered me so ...

The ways in which the older people thought about their future and the likelihood of a deterioration in health and death probably reflect their personalities and the coping strategies which they have developed over a lifetime, Fears about increasing infirmity and death can't be smoothed away that easily, However, some of the fears expressed, such as whether services will be available in the event of increasing infirmity or of dying before a dependent spouse, can be eased to some degree, It remains to be seen whether there is the will to do so,

The need for a flexible vision for support services

The most powerful impression created for us by the older people interviewed was of their diversity in terms of circumstances, lifestyles and aspirations, This underlines the importance of the broad aim of the community care reforms to move towards user driven and not service driven responses to the needs of elderly people, What would be an appropriate home care response to one of our respondents might be rejected by another even though both appear on the surface to have identical needs for personal assistance, Perhaps, this can be illustrated by taking the example of two people no longer able to go shopping independently, If social services arranged for a neighbour to do this, it might work brilliantly for one individual who would have faith in their neighbour to understand their preferences and who would look upon the new arrangement as the off loading of something which had increasingly become a worrying chore, For the other, however, such an offer of help might be completely unacceptable because what they wanted was transport and support so that they could continue to go shopping for themselves,

Linked to this, we were struck by not only the modesty of what most of our respondents wanted from social services but also how these expressed needs were much wider than conventionally defined community care services, As this report has illustrated, they included the need for help with housing issues and a major preoccupation with concerns about mobility and transport, Also, respondent after respondent stressed the importance of companionship and social relationships to the maintenance of their morale, and hence their independence, This suggests to us that what is required is something more creative than just social services taking the lead role in community care with a user driven philosophy, Rather, this important role should be linked to a more corporate view of how local authorities can foster the independence and quality of life of older people, Over ten years ago the Centre for Policy on Ageing produced a report called Councils of Care: Planning a Local Government Strategy for Older People (Norton et al , 1986) which argued for such a perspective which would consider issues of transport, leisure and environmental planning as well as community care, Since 1986 the direct provider role of local authorities may have shrunk but equally its skills at facilitating joint ventures with the private and voluntary sectors has greatly increased, These skills need to be applied to developing communities which respond to the diverse needs of older people,

We recognise that the resource pressures upon social services may make it difficult for them to feel able to pick up this challenge, However, such a strategy opens up the possibility of maximising the resource input of others, including the rest of the local authority and the private sector,

As pointed out in chapter two, the same resource pressures upon social services has seen them concentrating their energy upon those defined as in greatest need, The government's own monitoring of the community care changes suggest that one consequence of this has been:

Some of the most vulnerable people with low level multiple needs were falling through the community care net, For example, an older person with moderate mobility, health, housing and financial problems would probably not be identified by existing assessment systems, The sum total of these low level needs engendered a considerable burden of stress, however, and such individuals were likely to slip into a high need category, often requiring more intensive (and therefore most costly) intervention at a later stage (Department of Health, 1994, p24),

Few of our respondents were yet in what social service professionals would consider a high need category but many did have a range of 'moderate' problems, These were often not being responded to or were being responded to in terms of service reductions because of the perceived need to transfer resources to those deemed more 'at risk', We are very sympathetic to the dilemmas faced by social services on this point but feel they need to re-consider whether they are really using their resources in the most effective way,

One important component of a revised strategy could be to look at various brokerage models for responding to 'low level' needs, For example, Mrs Shaw has been told that she could not have help to have a bath in her own home, but she could have a bath in a residential home at a cost including paying the taxi fare there and back, However, is it not possible Mrs Shaw has a neighbour in her locality who is a retired nurse? Such a person might be delighted to help Mrs Shaw retain her dignity and independence by bathing at home?

The crunch issue is how such local services and local resources can be identified and then made accessible to older people, One possibility is to achieve this through what Fletcher and Herbert (1996) have called local service networks that :

„, would have a local access point to which inquiries could be made about available support to assist with practical and personal care needs, The access point could provide simple information about accredited providers of services in the locality, Preventive and independence - supporting services (meals, gardening, household maintenance, adaptations, shopping, technology) as well as more traditional services „, would be accredited,

We would suggest the need to test out this model with the proviso that a key local resource is likely to be the skills of individuals who might wish to contribute to their community on a more informal basis than implied by accreditation, A way needs to be found not to exclude them from the network, There might also be scope for linking people up on a reciprocity rather than fee payment basis as we saw in the report, So that for example, an older person might child mind in return for some minor repair work on the house,

However, it is likely that most required services will be paid for, It was clear that some of our respondents such as Mrs Goldberg, Mr Hadley and Mr Finch were becoming quite adept at buying flexible assistance from the independent sector in a way that was not an option for those dependent upon state benefits, Although this is an excellent development for those and similar individuals, it does raise the prospect of a growing social care divide, The better off will meet their multiple 'low level' needs through paying for care in the new mixed economy of welfare - the less well off will be

forced to wait until a major life crisis propels them into the high need categories which generate a response from social services, Local service networks could help to narrow this gap but only if those on low incomes are able to afford the identified services,

This report has been trying to give older people a chance to talk about what home and independence means to them, Perhaps, we should leave the last quote to Mrs Shaw:

If only we could get over... that we (want to) be helped without losing identity,

We hope this report makes a contribution to the development of housing and community care policies which manage to offer support to older people without undermining their self esteem and independence,

Case Study

Mr and Mrs Murphy

Mr and Mrs Murphy live on a small estate on the outskirts of a northern market town which is situated a short distance from the town centre, They have lived in the area all their lives and in their present home for 39 years, Their home is a three bedroomed council house on a small estate, and they particularly like it because it is very quiet and there is no traffic as it is a cul-de-sac, They are very attached to the house because it is where they brought up their three children,

Margaret and George have health problems in that they both suffer from arthritis, Georges condition stems from the years he spent working as a long distance lorry driver which eventually damaged the nerves in his back, He went on to manage the stores department at his firm, but later developed arthritis in his spine and had to leave work due to ill health, Margaret helps her husband wash and dress, but she also has arthritis in the top vertebrae of her neck so is unable to bend down, and she also suffers from angina,



They help each other, and are dependent on each other, Family and neighbours also help out when necessary, fetching shopping and other small tasks, George has a small electric scooter which helps him get around, Their three children all live very close by and will all help with jobs like gardening and decorating while their daughter sometimes stays overnight if they are feeling unwell, However they like to do as much as they can for themselves to keep as independent as possible and they don't really want to be reliant on their family, *"We only ask for what we need, if we don't need it we don't ask"*,

The local authority has recently installed a lift in their home and this is located in their living room and leads up to the spare bedroom, They have also had some adaptations in the bathroom, In addition a ramp and rails were fitted outside which enabled George to get straight from the kitchen door to his scooter, These adaptations have enabled them to stay in their home about which they are very happy, However they remain worried about both the coldness of the house and their general finances, There is only one radiator downstairs and no central heating in the bedrooms, They feel the cold badly as they are both quite immobile, Although the council will be upgrading the windows to double glazing this year and could fit additional radiators upstairs, they don't feel they could afford the running costs of full central heating which would add £8 a week to their rent, Their finances are very tight indeed, *"we live from day to day, from hand to mouth, we buy what we need and never go out"*, George has received incapacity benefit which will end this year when he reaches 70, The couple therefore do not qualify for income support or other benefits that accompany income support, such as cold weather payments, They find it difficult to obtain the right advice to help their situation, *"If you go to the DSS they don't tell you anything, if you find that you are entitled, they will say oh yes apply for it, but if you can't find out, how can you ask?"* Apart from financial concerns, Margaret does worry that she could be turned out into a residential home, if her husband died before her, This is because the council have spent money on the lift, and she feels they may want the house for other people, This is something that is always at the back of her mind,

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Area	Client name	Age	Household		Ethnicity		Household tenure				
			1 per	2 per	White	Afro Carib	OO	Soc Rent	Shelt Rent	Shelt Priv	Priv Rent
Midlands city	Mr & Mrs Smith	66/60		*	*		*				
	Mr & Mrs Jones	83/84		*	*			*			
	Mr & Mrs Wallace	78/82		*	*			*			
	Mrs Evans	63	*		*			*			
	Mr Collins	79	*		*			*			
	Mrs Johnson	79	*		*		*				
	Mrs Goldberg	75	*		*		*				
	Mr & Mrs White	70/83		*	*						*
	Mr Green 1	72		*			*	*			
	Mr Price	90	*				*	*			
	Mrs Young	68	*		*		*				
London borough	Miss Ashman	98	*		*						*
	Miss Mills	93	*		*						*
	Miss Marsh	75	*		*						*
	Mr Finch	89	*		*						*
	Mrs Jordan	93	*		*			*			
	Mrs Saunders	89	*		*			*			
	Mr & Mrs Hall	69/67		*	*			*			
N,W, market town	Mr Hadley	73	*		*		*				
	Mr & Mrs Harrison	72/83		*	*		*				
	Mrs Clark	75	*		*		*				
	Mrs Morris	72	*		*		*				
	Mrs Grant	73	*		*		*				
	Mr & Mrs Booth	74/76		*	*		*				
	Mrs Martin	89	*		*		*				
	Mr & Mrs Bell	69/76		*	*		*				
S,W, city	Mrs Higgins	74	*		*					*	
	Mr Wilson	68	*		*					*	
	Mrs Lambert	83	*		*		*				
	Mrs Shaw	89	*		*		*				
	Mrs James	88	*		*					*	
Total			22	9	29	2	16	6	4	3	2

1 only Mr Green was interviewed from his two person household

Appendix (continued)

The 31 households profiled in the **table** were identified through **professional intermediaries**. These included Anchor staff involved in two Staying Put projects, a Moving On project and three retirement housing schemes, **It** also included staff from a Care and Repair project in a South West city and housing departments in three of the **case** study localities, These professionals were asked to approach clients to see if they were willing to be contacted by the research team,

The research team deliberately set out to interview older people from a range of housing situations, They also asked the **professionals** to approach people who had emerging support needs,

The households interviewed as a result of this process are not representative of older people, although the research team did deliberately set out to interview people from a range of housing situations, The sample is biased, **for** example, towards people who have used home improvement agencies,

All the names used in the text are fictitious apart from the four **case** studies at the end of chapters three to six. The detailed working of these case studies was checked with the people in question



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