

CHAPTER FIVE

EXTERNAL SOURCES OF SUPPORT

INTRODUCTION

The previous two findings chapters have examined the relationship between older carers access to material resources and the way in which they performed and experienced their role. It has also been shown how, contrary to conflictual approaches to poverty and older age (chapter 1), the influence of material resources was mediated by the age-specific factors of culture and disability. This chapter examines these issues with reference to respondents' access to external sources of support and the influence of poverty and older age on this access. The first section examines carers' access to informal support and how they experienced this. This is followed by an exploration of potential barriers to access and the influence of social divisions upon this issue. Carers' feelings towards receiving informal support and their overwhelming attitudes of self-reliance are also examined. It is concluded that, while material circumstances play an important role in influencing access to informal support, as with respondents' financial management and caring strategies, factors such as culture and disability must also be taken into account and that contrary to postmodernist claims, the impact of these factors is typically characterised by age-based homogeneity rather than diversity.

In view of the problems experienced by older co-resident carers in coping with their role, they are often forced to turn to formal sources outside the household. Chapter three, showed that limited resources can reduce respondents' ability to access such support due to the introduction of charging and means-testing. This restricted access could be compounded by cultural factors such as older people's general financial caution rendering them unwilling to spend on anything but the necessities of life. It will be the purpose of the second part of this chapter to further examine respondents' access to formal help. It outlines the type of help received and explores carers' attitudes to the forms of support available to them. Possible barriers to gaining access to formal support will then be examined. It is shown how the fragmentation of services arising as a result of welfare pluralism, rather than promoting choice has given rise to confusion as to what services are available and the way in which they can be accessed. The practice of charging and means testing and respondents' relative poverty also constituted a barrier to access and these barriers were exacerbated by age-related, culturally derived factors such

as attitudes of financial caution, self-reliance and an aversion to ‘charity’ and the ‘workhouse’. It is subsequently argued that, in spite of a rhetoric of client choice and empowerment, older carers’ basic need for adequate, appropriate, accessible and affordable help has not been met. At the same time, the split focus of service provision on the diverse and potentially conflicting needs of carers on one hand and disabled people on the other serves to neglect their complex and overlapping identities and the way in which their interests and requirements coincide.

ACCESS TO INFORMAL SUPPORT IN OLDER AGE

As Walker (1982) maintains, in practice, community care is overwhelmingly care by kin, rather than by the community with access to informal networks of support representing an important factor in mediating the demands upon older people (Wenger, 1992). As such, Wenger (1992) observes that in planning interventions for older carers, it is important to take into account not only the central caring relationship but also the presence or absence of supportive networks of kin or non-kin. Such networks can be an important source of emotional as well as practical support (Wenger, 1984; Nolan et al, 1996). For example, the impact of adverse life events has been closely associated with the incidence of depression (Paykel, 1978) but is lessened if the individual has access to emotionally supportive networks (Henderson et al 1980; Brown and Harris, 1978). However, while much work has been done in the field of gerontology and sociology to explore the support networks of older people, the focus on carers in general and older carers in particular is much more limited (Wenger, 1989; Olsen, 1996; Phillipson et al, 2001). In order to explore these issues, initial interviews asked carers if they had relatives living locally and the amount and type of help, which was received from relatives, friends and neighbours. They were also asked about the length of time they had been living in their current accommodation, in the assumption that the longer they had lived there the more likely they were to have networks of informal support:

Help from kin

As it can be seen from the above tables, only five respondents did not have relatives living in Sheffield.

Table 5.1: Respondents with relatives living in Sheffield

Relatives living in Sheffield	29
No relatives living in Sheffield	5

The majority, 26 claimed to received regular support from relatives living locally:

Table 5.2: The incidence of practical help from relatives in the last month

PRACTICAL HELP FROM RELATIVES	NUMBER OF RESPONDENTS
None	8
1 to 4 times	18
5 to 9 times	5
10 or more times	3

As other studies suggest (Litwak, 1965) the help provided by wider kin involved, not intimate aspects of personal care, but more distant aspects of social care such as assistance with shopping, transport and heavy housework tasks such as laundry. As Mr Tumin said of his niece:

She comes about once a week or once a fortnight. She comes to collect my washing every fortnight but the other washing I do for myself (Mr Tumin)

While informal care has been portrayed both by consensual theorists and post modernists (chapter 1) as being idiosyncratic and spontaneous in its delivery, in accordance with the hierarchy of caring model identified by Qureshi and Walker (1989), the identity of informal care providers in this study followed a definite pattern with respondents' children being the most common source of support and with daughters being preferred to sons. Thus, Mr Caplow and Mrs Harris, both of whom had sons and daughters, were largely reliant on their daughters for practical assistance:

My daughter always brings me a few things in and they will last me till Wednesday till my other daughter comes (Mr Caplow)

She does all the shopping, she collects our pension and the rest of the shopping I get delivered from the local shops (Mrs Harris)

Sons and daughter-in-laws were cited as ‘second choice’ carers, when daughters were not available:

Our son helps; he lives just half an hour away. He does the shopping and the gardening and heavy housework and he takes us to the hospital and the opticians but he works (Mrs Lane)

My daughter-in-law does the supermarket shopping (Mr Hunter)

For those without children, nieces and nephews were commonly cited:

We have a nephew and his wife who are like a son and daughter to us. They are very good (Mr Tunstall)

I have a niece who does the heavy washing for me, the bedding and stuff. I don't have any family so actually she's a substitute daughter and she looks after us but she lives in Killimarsh so she can't be here every five minutes and her own mother's very ill, she's bed-bound so she's a bit restricted in coming here (Mr Tumin)

Due to the health problems of older relatives, help from same generation sources such as siblings was rare. Only two respondents who were at the younger end of the age-scale discussed the receipt of help from such sources:

My sister lives not very far from the church in Fulwood but she's not very well and walks with a stick so I don't see much of her (Mrs Coates)

My sister died when she was 70 odd, I could have had help from her (Mrs Gibbons)

Indeed, as it was seen in a previous chapter, the process of ageing led to a general diminishment in support networks through such things as the loss of work contacts due to retirement, through the death or ill health of kin, friends and neighbours and through respondents' own ill health and mobility problems. This isolation was compounded by the decreasing availability of informal support due to social trends such as increasing geographical mobility and the large-scale entry of women into the workforce and the

corresponding diminishment in the number of children caring for elderly parents (Milne et al, 2001). As such, in line with other studies (Twigg and Atkin, 1994), while most carers claimed to receive some support in their role from kin, this was often minimal and sporadic:

They've got their own problems; you can't expect them to do much. They might come in an emergency but then it's getting hold of them (Mr MacLellan)

Well you can't expect them to give their lives up for you can you, they've got their lives to live and they've got their work to do (Mr Caplow)

They are busy looking after themselves. (Mr Hall)

My son lives at Dronfield, he's got three children and he doesn't get into Sheffield much. He works for himself and obviously he's got to get work where he can. So he doesn't help us much (Mrs Gibbons)

Both my daughters help as much as they can but they've got their own families (Mrs Hudson)

I wouldn't say she (his daughter) visits a lot. I mean she's got a lot to do. She's working three days a week and her husband, he's an engineer, works shifts at the airport but of course they do come when they can. They live in Solihull (Mr Dale)

Consequently most respondent households were a relatively isolated and self-contained unit, with members of the household being heavily reliant upon each other but tending not to rely too heavily on wider kin. For some this appeared to be due, not simply to the lack of availability of such kin, but also due to choice, partly due to an unwillingness to 'impose' on relatives:

You're a hindrance on the younger ones if you go on holiday with them, you can't get around you see (Mr Caplow)

I don't particularly like imposing on people. I feel it's an imposition and it's my problem... I don't involve them. They would help me yes but I will not involve them. I know it's my fault but that's my principle and I'm sticking to it. I've told them that they will learn from the situation that I find myself in. When I get to a certain age, there's no question I shall go into a home. They will not have to put up with what I have had to put up with (Mr Davis)

Others expressed the positive wish to be independent:

We try to be as independent as we can but it is getting top-side of us at present (Mr Hall)

"I want to be independent for as long as I can. (Mr Dale)

'We don't like to depend on anybody else' (Mr Tunstall)

This reluctance to turn to others for help has been found to be particularly apparent amongst older people, who tend to be characterised by strong attitudes of self-reliance and personal resourcefulness (chapters 3 and 4). As Lewis (1998) identifies, this self-sufficiency of carers may be a vestige of their former lives and could also be associated with advancing years and ultimately death and the 'social disengagement' possibly arising from this (chapter 1). Thus she maintains that couples who, in the past, had been totally self-reliant, especially as a result of geographical mobility, may be particularly unwilling to rely on outside help. This self-reliance was well illustrated by Mr Denis who had totally lost contact with friends and kin since emigrating from Jamaica in the 1950s (case study 5.1). However, contrary to the claims of Lewis (1998), similar sentiments of self-reliance were also expressed by the majority of carers in the sample, including those who had always lived in the same locality. As such, reliance on kin - based informal sources was commonly regarded by carers as being a 'last resort' and not as preferential to alternative sources of formal provision. These observations lead Phillipson et al (2001) to suggest that rather than placing the significance family care above all else; policy should focus on questions such as what support is provided, who is involved and what are the limits to such involvement. In spite of this decreasing

availability of kin-based support networks and the reluctance of older people to depend on such networks, social policy and its emphasis on care *by* the community has ignored these trends and wishes and continued to promote the family as the prime source of support for older people (Phillipson, 1998). While the rhetoric behind this policy is that the family is the most desirable source of support, critics maintain that it is simply a cheaper option to the government than the adequate provision of formal support:

Current policy assumes that 'the community' contains reserves of caring capacity, which, if encouraged, would reduce the need for many statutory services. It also assumes that disabled or older people themselves *prefer* informal rather than formal sources of help. The available evidence does not support these assumptions (Parker, 1993: 61)

This role of social policy in imposing preconceived ideals and actions onto individuals, regardless of their preferences serves to highlight the Marxist portrayal of the state as an agent of social control, rather than altruistically and sensitively responding to the needs of individuals as functionalists would maintain (chapter 1). Indeed prevalent social trends are likely to further undermine this policy emphasis on family care. For just as the nuclear family had evolved to meet the needs of industrial society, it will continue to adapt to meet its changing needs. Consequently, the modern family no longer conforms to any single formula but, as post-modernists observe, is characterised by increasing diversity (chapter 1). This is confirmed by official statistics which show a rapid rise in single person households, the proportion of which has doubled from 14 per cent in 1961 to 29 per cent in 2000 (Social Trends, 2001). There has also been a corresponding decline in traditional nuclear families. However, further investigation reveals that these transformations are largely apparent in younger rather than older households. For example, the increasing proportion of single person households is largely apparent amongst those under 65. Thus the proportion of single person households comprising of a man aged under 65 has tripled between 1971 and 2001. This compares to the proportion of single person households headed by a man or woman aged 65 or more which has stayed roughly constant during this period (Social Trends, 2001). The household composition of older people also shows a greater degree of homogeneity than younger counterparts. Thus, as table 5.3 shows, nearly all pensioner households, 97.6 per

cent, are comprised of one or two adults. This compares to non-pensioner households, which tend to be characterised by much greater diversity.

Table 5.3: Composition of pensioner and non-pensioner households (n=6637)

	NON-PENSIONER HOUSEHOLDS	PENSIONER HOUSEHOLDS
One man	11.7 %	14.9 %
One woman	12.4 %	54.8 %
One man & one woman	29.9 %	27.9 %
Two adults & children	24.5 %	0.2 %
One adult & children	7.4 %	0.3 %
Two men or two women	2.1 %	1.4 %
Miscellaneous	12 %	0.5 %

Source: secondary analysis of the Family Expenditure Survey, 2000-2001

To continue an ongoing theme of this thesis, this vein of homogeneity and continuity within a wider context of heterogeneous and changing household types can be attributed to a combination of material, cultural and pathological factors. Thus with regard to physical pathology, the consistently high incidence of single person households amongst older people, especially older women can be largely attributed to the death of a partner. While cultural attitudes of self-reliance render older people unwilling to rely on outside sources and subsequently reinforce the self-containment and isolation of the household unit (chapter 4). This isolation may be further exacerbated by attitudes of ‘individualisation’ amongst younger generation kin (chapter 1) who may feel a lesser pressure to conform to norms of kinship obligation. Finally, with regard to material issues, while social trends and changing work patterns have undermined wider kinship networks, due to older peoples’ workforce marginality, such social changes (chapter 1) will, at least in part, have bypassed the individual households of the current generation of older people. As a result of these combined influences, as with consumerist cultures (chapter 3), post-modern trends in household fragmentation and individualisation may have had little impact on the households of many older people who represent stability in the context of wider kinship break-up and fragmentation.

Help from non-kin

This break-up of the wider kinship support networks of older people has implications for the caring role. For, as Phillipson et al (2001) maintain, over the past fifty years society has moved from an older age experienced within family groups to one which is more ‘voluntaristic’ and shaped by ‘personal communities’, that is, friends, neighbours and leisure associates. Similarly, research such as that by Nocon and Pearson (2000) has placed emphasis on the importance of friends and neighbours as well as kin as a source of informal help for older people. Such neighbourhood help was occasionally alluded to by respondents:

I go out with a neighbour upstairs. His wife comes down and sits with her while we have a drink, but that’s all, it’s negligible really (Mr MacLellan)

Next door because Pete can’t do anything and I’m pretty helpless there’s a man and his wife and the man will do anything for me. The man comes and changes bulbs for me...he’s very good. But all the rest are old women on their own. (Mrs Harris)

However, although most respondents were well-established members of their neighbourhood (table 28), such practical assistance from neighbours was relatively rare with only six households claiming to receive regular support from such sources. Thus, as Abrams et al (1989) observe, social trends have transformed neighbouring today into more a matter of choice than constraint and more influenced by the need to define privacy than by need for help.

Table 5.4: The incidence of practical help from neighbours in the last month

PRACTICAL HELP FROM NEIGHBOURS	NUMBER OF RESPONDENTS
None	28
1 to 4 times	5
5 or more times	1

Consequently, it is logical to assume that, just as social trends such as the increasing entry of women into the workforce has undermined the kinship networks of older people, such trends have equally effected ties with younger, non-retired neighbours:

They've either died off or left, there's only a few we know, they're all new and they work. If I stood at the gate, they'll talk to you and they'll say how are you but that's all. They're all working, they're busy (Mrs Lane)

They do help but they are busy people. Mrs Booker across the road is very helpful but she teaches at the High School and she leaves the house at about 7 o'clock in the morning so she can't do much during the day. (Mrs Field)

Many respondents also compared their previous experiences of 'neighbourliness' to their current situation. This was due to the changing character of their neighbours and neighbourhoods and due to the fact that previous neighbours had either died or left:

We used to have a neighbour over there who used to come in and talk. She used to come in every day for a bit of company and I'd go across to her but they're not like that here. Mrs Ellis will speak to us and she'll come to the door but sometimes it's a week before I see her. If we never went out, we'd never see her. Occasionally she might come to the door. I wouldn't call it neighbourly, not like the neighbours we'd been used to in years gone by. They'll stand at the door and speak to you but they won't let you in (Mrs Taylor)

I know one or two but it's not like the old times. Things have changed, you don't know your neighbours (Mr Carson)

We don't see a lot of the new people who have moved in because of course we've never met them. Middle-aged we knew everybody in all the houses and we used to go into each other's houses and go to dinner parties quite a lot but then they died or left or went into retirement places and we stuck here and kept on sticking here. (Mrs Field)

The secondary analysis of General Household Survey uphold these suggestions, showing that those aged seventy and over experience less support than any other age group, as the table below indicates:

Table 5.5: Access to social support by age group (n=2737)

AGE BAND	NO ONE TO HELP IF ILL	NO ONE TO HELP WITH FINANCIAL PROBLEMS	LESS THAN 3 PEOPLE TO TURN TO IN A CRISIS
16-29	10.3 %	10.4 %	14.9 %
30-39	18.2 %	12.6 %	18.3 %
40-49	15.0 %	12.5 %	15.9 %
50-59	19.0 %	15.2 %	15.9 %
60-69	15.8 %	17.5 %	12.7 %
70 +	21.7 %	31.9 %	22.4 %
Total	100 %	100 %	100 %

Source: secondary analysis of the General Household Survey 2000-2001

In view of the lack of support experienced by respondents, both from kin and non-kin, Abrams et al (1989) have advocated the stimulation of more formalised sources of neighbourhood support through a process of ‘interweaving’. Evidence of such sources were occasionally cited by respondents, such as Mrs Phillips, who lived in a warden-controlled housing complex for older people and Mrs Coates who spoke of her local nursing home helping out when her husband fell out of bed at home:

Were in Neighbourhood Watch round here. We don't pay anything to be in it but we make a bit of money by having a raffle...so there is somebody giving you help, you know (Mrs Phillips)

Was it yesterday, I couldn't get any help next door so finally I rang the nursing home up and they came straight away, a man and a woman. So they're always willing to help me even when I'm not paying them (Mrs Coates)

Other respondents spoke of the importance of local community organisations such as sports clubs, luncheon clubs and community centres in their lives. Such resources in the

community can provide their members with practical and emotional support, thus helping them to cope more effectively with their personal, group or community problems (Kanopka, 1963). However as Davidson (2001) observes, many such organisations, specifically geared to the welfare of older people are ‘top heavy’ with women, with anecdotal evidence suggesting that many men do not find these organisations as being appropriate to their needs. For example, Mr Caplow spoke of the way in which he felt excluded in his local community centre which was dominated with women who he found to be unfriendly:

Sometimes I don't see anybody all over the weekend. There's a community centre but even then you feel lonely because in communities you get cliques. I go down there sometimes on a Thursday to play whist but you still feel out of it...as I say I go down there every week, now and again and the majority are women, the majority of them are widows, but it doesn't do to press your company on anyone because they get the wrong idea. If a man starts pressing friendship they start thinking something else don't they. I went there yesterday. There were eighteen there and out of that 18 there's three men.

CLASS, POVERTY AND INFORMAL NETWORKS

Like research on the impact of poverty on the family unit (chapter 1), research on the impact of such poverty on kinship networks has been contradictory. Some commentators have suggested that poorer people tend to be well endowed with supportive networks. For example, Young and Wilmott (1962) found that working class families in the 1950s in East London tended to be characterised by highly developed and predominantly female networks of kin serving to provide mutual support during times of poverty and hardship. Similar patterns were found by Qureshi and Walker (1989) in 1980s Sheffield where it was found that working class families, especially their female members tended to be characterised by low level of geographical mobility and high levels of reciprocal exchanges of help and support with older kin. However, others warn against the adoption of idealised perceptions of the closely knit interdependence of working class communities, for such interdependence can be seen as being borne out of necessity rather than choice with mutual autonomy being the ideal for most carers and care recipients

alike (Arber and Ginn, 1992). Moreover, some recent research maintains that contrary to the above findings, poorer sections of the population are in fact less likely than the more affluent to have access to informal support, its distribution being linked in systematic ways to social class and mediated by other social divisions (Oakley and Rajan, 1991; Arber and Ginn, 1992; Phillipson et al, 2001). For example, Qureshi and Walker (1989) qualify their above findings by observing that the extreme poverty and social marginalisation arising from long-term unemployment can actually undermine informal caring networks by reducing the incentive and ability of poor people to maintain such networks. In addition, the social isolation that can arise from poverty (chapter 3) can lead to a similar erosion of informal networks. For example, recent statistics indicate that manual workers are less likely than non-manual workers to experience high levels of reciprocity or social support (GHS, 2001-2002).

In order to explore these divergent hypotheses and to establish whether there was a class or materially-based differential in the incidence of informal support received by respondents, quantitative and qualitative data were analysed and the experiences of council tenants and owner occupiers were compared. This analysis challenged idealised portrayals of the mutually supportive nature of working class life (Young and Willmott, 1962). For while material expedience served to reinforce the bonds of household members (chapter 3 and 4), within poorer households, it loosened bonds with those outside the household. Thus, the 17 council tenants in the sample did tend to have less contact with friends, neighbours and relatives than their 17 owner occupying counterparts. For example, it was found that of the eight respondents in the sample receiving no help from kin, the majority, five, were council tenants. Moreover, of the six households receiving regular support from neighbours, only one was a council tenant, the other five were owner-occupiers. Analysis of qualitative data revealed similar differentials. Thus council tenants commonly expressed feelings of isolation both from kin and non-kin and were more likely to describe their locality as one in which residents kept themselves to themselves. Further analysis revealed a number of possible explanations for this difference in the experiences of council tenants and owner occupiers, all of which were related to the material circumstances of respondents.

Poverty and marginality

Council tenants were more likely to be relatively poor and suffering from the problems of access and ‘restrictedness’ which can arise from this poverty (chapter 3). Thus, at £184 per week, the average household income of council tenants was substantially lower than that of owner-occupiers whose average income was £212 per week. Council tenants were also less likely to have access to a car than owner occupying carers with only 1 of the 11 car owners in the sample being council tenants. Moreover, the cramped living circumstances of council tenants rendered them less able to accommodate visiting friends and relatives. For example, Mr Denis, a Jamaican immigrant, spoke of how he was unable to accommodate his son who also wished to move to England, in his one-bed roomed flat:

Case study 5.1: Mr Denis and Mrs Field – the materially diverse carers

Mrs Denis was 85 and Mrs Field 82. Both had been looking after their confused and physically frail spouses for ten years. Although Mr Denis had been living in the same council flat for 20 years, he had no contact with his neighbours with whom he was on poor terms. Since he emigrated from Jamaica 36 years ago. He had also lost contact with wider networks of kin. Indeed, although he had a son from a previous relationship, he had not seen him for many years:

“I don’t have any contact with him. Years ago he wrote and asked me if he could come over and stay with me but I said no, we didn’t have the room” (Mr Denis)

These experiences contrasted to those of Mrs Field who had lived in her large owner occupied house for fifty years and was in contact with a few of her neighbours, one of whom worked as her ‘chauffeur’. In addition, unlike Mr Denis, she was well able to accommodate her three children when they visited and was also able to employ ‘live-in’ help (chapter 3)

The isolation of many poorer carers from wider networks of kin was well illustrated by a parochial perception of locality expressed by many such carers. Thus working class and very old carers tended to have a downsized perception of locality, regarding anyone not living on their particular estate or suburb as not living locally. For example, when Mr Tunstall who lived on a council estate to the south of the city was asked if his nephew lived in the area he replied, *‘No, he lives in Eccleshall’*. This contrasted with the experiences of younger and more middle class carers such as Mr Davis and Miss Howard who saw their relatives regularly even though none lived in Sheffield.

Not only did the greater poverty of council tenants undermine their ability to maintain and extend their support networks, it also undermined the ability of these networks to provide any support. Thus it has already been seen in chapter three that, due to their limited access to material resources poorer people are more likely to be practically rather than materially orientated in the care which they provide, with help tending to take the form of time, goods and physical space rather than money (Gubman and Tessler, 1987). Due to class stratification, there is a strong likelihood that the kinship networks of such low-income carers are also relatively poor and similarly limited and constrained in the type of help that they could potentially provide. While the largely practical orientation of this help is less able to transcend the barriers of geographical dispersion and family and work responsibilities. Thus, as Phillipson et al (2001) state, the ‘social convoys’ of working class older people tend to be more subject to disruption and fragmentation in respect of support. Similar problems tend not to be experienced by better-off carers who, due to the more esoteric forms of support exchanged by kin are more able to transcend such obstacles and were more able to facilitate ‘care at a distance’. Thus, as Mrs Field said when asked if her three children, all of whom worked and none of whom lived in Sheffield, helped her out at all:

Well not physically I suppose but they are very good. They come up quite regularly when they can and if I need anything getting, I'm very fortunate in one respect, they will get it for me. Like one of my daughters was just going off abroad and bought me these socks at the airport, these coloured cotton socks came from Heathrow because we knew he needed some more and she just decided to buy them.

Instrumentalisation in caring relationships

As Parker (1990) observes, the greater access to material resources commanded by the more affluent is likely to potentially enhance the occurrence of reciprocal exchanges within the caring relationship (Arber and Ginn, 1993). Such patterns of exchange are also likely to be reproduced amongst wider networks of kin through the ‘instrumentalisation’ of informal caring relationships, which can be seen as an embodiment of the increasingly individualistic and narcissistic nature of such

relationships as alluded to by third generation theorists (chapter 1). This issue of instrumentalisation has been explored by a number of researchers (Finch and Mason, 1993; Pratt and Norris, 1994; Langan et al, 1996) who maintain that such exchanges help to maintain acceptable boundaries and promote feelings of self-esteem and independence in such relationships. Conversely, self-perceptions of dependency appear to be related to feelings of having nothing of value to exchange, with the result that those most needing care may be least likely to be able to reciprocate (Wilson, 1993). Although not directly addressed in the interview schedules, transcripts revealed the high incidence of material reward being given by carers to informal supporters in return for their practical help. For example, the daughter of spouse carer Mr Carson gave up her job so that she could assist in the care of her mother and for her 'wages' she was given her mothers attendance allowance:

You see my daughter used to work and when the attendance allowance came through I said why not give up your job and work for me. Its just the same as paying someone else to come in isn't it. She comes in practically every day. She definitely looks after me (Mr Carson)

Another spouse carer, Mrs Coates, gave her son who lives in London her entire state pension every week in return for the occasional help which he provided with shopping and gardening.

I give my pension to Charles for his help. He pays the gardener. (Mrs Coates)

Similarly, Mrs Roach paid her niece for taking her shopping. Finances were not the only form of material payment used with Mr and Mrs Lane signing over the house to their son in return for the help that he provided:

Actually the house isn't ours, we gave it to our son 10 years ago, he's such a lot of help, he does all the repairs, it took the responsibility off us (Mrs Lane)

In addition, Mrs Field let her gardener's wife have free use of her car in return for regular 'chauffeuring duties':

I said I think I've got a good idea. I said, you take my car and keep it in your garage and take responsibility for it, use it when you want. In return, perhaps you could take me about to the hospital and things like that (Mrs Field)

One implication of this instrumentalisation of informal caring relationships was that it seemed to satisfy the common wish expressed by many carers to be independent and non-burdensome to informal supporters. However, it could also present a further barrier to poorer carers in accessing informal help with their poverty rendering them less able or willing to materially reciprocate for any such help provided (Oakley and Rajan, 1991). For example, Mr Cicourel complained that he only saw his wife's relatives when they wanted some sort of help, which he was unwilling to provide:

The only time I see them is if they want a favour or if they want anything, they won't come just to see how Hilary is, because Hilary's useless to them (Mr Cicourel)

Thus of the seven carers claiming to provide material reward to informal carers for the help which they provide, only one, Mr Carson, was a council tenant. This instrumentalisation of informal caring relationships undermines the perception of informal care as being based on expressive feelings rather than instrumental reward and supports Finch and Mason's (1993) argument that the process of negotiating support applies to kin as well as non-kin. It could also help to explain the occasional lack of congruence expressed in interviews between subjective perceptions of closeness with friends and relatives and the degree of practical help provided by them. Thus some carers felt emotionally closer to people who provided them with relatively little practical help and less close to people who were much more helpful.

Housing and neighbourhood

Table 5.6: The number of years in current accommodation

YEARS IN CURRENT ACCOMMODATION	NUMBER OF RESPONDENTS
0 to 9	7
10 to 19	5
20 to 29	11
30 to 39	5
40 to 49	2
50 plus	4

The issue of housing has been identified by as having an important influence on perceived material well being of respondents and the way which they experienced their caring role (chapter 3). Housing can also be an important influence on living environment and access to support. In order to explore these issues, carers were questioned about their current housing status and the length of time they had spent in their current accommodation. As it can be seen most respondents were relatively well established residents of their neighbourhoods having lived in their current accommodation for between two and sixty years and with the average length of occupancy being 25 years. However, there was a notable difference in average occupancy time between council tenants and owner-occupiers. Thus at 18 years, council tenants had been in their current homes for much less time than their owner occupying counterparts for whom the average was 33 years. This was largely due to the greater likelihood of council tenants to move due to disability and a lesser ability to be able to adapt previous homes. (eg. Mrs Reid, Mr MacLellan, Mrs Halsey, Mr Caplow, Mr and Mrs Taylor, Mr Tunstall, Mr Denis). Not only were council tenants likely to perceive this transition in a negative light (chapter 3). They also had less choice and control in this process of transition and were often relocated in places far removed from established networks. For example, Mrs Halsey spoke of how she had to move to the Batemoor estate due to her husband's mobility impairment:

We knew all them behind, yes, we had to leave them all behind. I mean if anybody was ill on our block everybody mucked in and helped out, everybody helped one another. No one wants to move through illness, nobody wants that (Mrs Halsey)

In order to further explore the neighbourhood environment and possible material variations in this between respondents 'Acorn profiles' were used. These were drawn from the 'upmystreet' website (2002) and provided a full socio-economic profile of respondents residential areas based on postcode address. As table 5.7 illustrates, respondents were drawn from a wide array of area types ranging from type 3 'mature, affluent, home owning areas' to type 49 council estates characterised by high levels of unemployment. It can also be seen that with the exception of area type 34, there was no overlap in the area types of council tenants and owner-occupiers with the latter tending to

be dispersed widely in terms of geography and area type, while council tenants in the sample tended to be concentrated into areas of relative deprivation. The most common area type for council tenants was ‘type 40’, which for many respondents in this sample such as Mr Caplow, Mr and Mrs Taylor and Mr Tunstall referred to a council estate on the outskirts of the city. A further three respondents such as Mr MacLellan lived on the outskirts of this estate, classified as area ‘type 48’.

Table 5.7: Acorn profile of respondents’ residential area types by housing status

ACORN PROFILE	OWNER OCCUPIERS	COUNCIL TENANTS
Type 3: mature affluent home owning area	1	-
Type 5: mature well off suburbs	2	-
Type 14: home owning family areas, older children	2	-
Type 26: mature, established, home-owning areas	1	-
Type 28: established home owning areas	2	-
Type 30: established home owning areas, skilled workers	3	-
Type 33: council areas, some new home owners	-	1
Type 34: mature home owning areas, skilled workers	2	1
Type 35: low rise estates, older workers, new home owners	-	1
Type 37: multi occupied town centres, mixed occupations	-	1
Type 40: council areas, older people, health problems	-	6
Type 41: better off council areas, new home owners	-	1
Type 45: low rise council housing, less well off families	-	1
Type 46: council areas, residents with health problems	-	1
Type 48: council flats, elderly people, health problems	-	3
Type 49: council flats, very high unemployment, singles	-	1
Area type not traceable	4	-
TOTAL	17	17

Source: Acorn, 2002

While this notable number of respondents in one area of the city could have been an accident of sample selection, it could also be due to the fact that, contrary to post modern claims of increasing social diversity, there continues some degree of homogeneity in the

experience and the environment of poorer members of society, with older carers in need of support being likely to be concentrated into such areas. For example, it is argued that recent housing policy such as council tenants 'right to buy' has led to an increased polarity in material and social characteristics between council tenants and owner occupiers with those living in council accommodation being much more likely to be relatively disadvantaged (Pickvance, 1999). Thus, as the Acorn profile for area 40 describes:

A striking feature of this ACORN Type is the proportion of people suffering from a limiting long-term illness – at 25 per cent of the population this is over twice the national rate. These are low-income areas where over 35 per cent of the population earn less than £10,000 per annum. Car ownership levels are very low with 60 per cent of households having no car (Acorn, 2002)

The most notable of these adverse environmental factors emerging from interviews was the fear of or incidence of crime, violence and harassment from neighbours. No owner-occupiers reported such problems as compared to four council tenants, Mrs Halsey, Mr Denis, Mrs Phillips and Mr Hall:

There has been a lot of drug addicts around, we've put locks on the doors, so ours is locked at night. Drug addicts use the spaces under the stairs. There's a hell of a lot of addicts around here but I don't know them personally (Mrs Halsey).

I don't get on well with them. Well this one over here, they've been here for nine years and they torment me – knocking and noise and loud music..I complained to the corporation and they told me, do you want to move or do you want to stay here but I'm not going to go, why should I go. They're coloured like me. I don't talk to them. I don't like arguing with people. No I don't have anything to do with them. I just keep myself to myself. (Mr Denis)

I've had some bad neighbours. They've been in five years and they've just evicted them. There were four children from 9 to 15 and they were jumping through windows and throwing stuff – a rolling pin came through a few weeks ago. Just

before they went, these kids they had guns and they were up trees shooting windows out, they did nearly £2000 worth of damage, the police were never away from here but as I say, it takes a long time to get somebody evicted (Mr Hall)

There was a stage when we couldn't even sit here and look out the window. We had eggs thrown at the window, we had paint thrown at the window stones thrown at the window. I fetched the police; I kept ringing for the police and it were them down there. (Mrs Phillips)

Significantly, all of these anecdotes allude to problems with children and younger people. When this is combined with the decreasing supportive capacities of younger, non-retired neighbours, this suggests that older people may indeed benefit from residence in a community of other older people rather than in mixed neighbourhoods (Qureshi and Walker, 1989).

ACCESS TO FORMAL SUPPORT

Table 5.8: Formal support received by respondents

TYPE OF FORMAL SUPPORT RECEIVED	NUMBER OF RESPONDENTS
Home carers	26
Respite care	10
Day care	9
Community nurse	7
Voluntary sitter	2
Carer support group (formalised)	3

As Qureshi and Walker (1989) maintain, in spite of apparently rigid analytical distinctions drawn between formal and informal welfare by theorists such as Abrams (1978), the two sectors are in fact part of an interdependent and dynamic partnership in which informal care is given the primary role (chapter 1). In this respect it has been argued by successive governments that the over-availability of such formal provision can undermine the supportive capacities of informal networks and promote over-reliance and dependency on the state. However, contrary to these assumptions, carers reliance on

formal provision was more likely to be promoted by carers' commonly expressed wish to be independent from informal supporters as well as social trends such as the increasing numbers of working women. Moreover, due to the specific and limited nature of informal support provision, carers did not necessarily view formal help as a substitute for informal help but rather as a complimentary and parallel service. Thus interviews revealed that carers and the person for whom they cared were in receipt of a variety of formal welfare services.

Provision aiming to give practical support to carers is, as Twigg and Atkin (1994) recognise, characterised by two main models (chapter 1). The first of these is the 'carers as resources' model with provision being largely aimed at the care recipient in order to promote their independence and relieve their subsequent reliance on informal sources of care. Examples of such services include home care, respite care and day care. Specific carer services such as carer support groups have become more popular in recent years due to legislation such as the Carers (Recognition of Services) Act 1995 and changing perspectives of service providers who are increasingly recognizing the needs of carers through the adoption of a 'carer as co-clients' model (Twigg and Atkin, 1994). Consequently, as Bauld et al (2000) observe, care managers are shifting their focus towards supporting carers with their needs being a higher priority for service providers than they have been in the past. As Milne et al (2001) observe, there is little evidence about the effectiveness of services specifically for older carers with much existing research relating to the needs of adult carers in general. Moreover, there is a general bias towards service-based and provider perspectives in most studies of new community care arrangements, rather than on the views of the users themselves (Baldock and Ungerson, 1994). In order to redress these omissions and explore issues of access to formal support, carers were questioned on their views towards the range of formal support which they received or perceived to be available to them.

Day Care and Respite Care

Unsurprisingly in view of the fact that all of the respondents were carers and most of them had apparently freely chosen this role (chapter 4), in initial interviews, all but one

carer refused to consider the immediate possibility of permanent care for the care recipient even though the option of such care had in many cases been offered to them.

There's no way she's going away permanent not unless she says so but from my point of view, no, its out of the question (Mr Tumin)

He could have gone away years and years ago when he was a child. We were given the opportunity years and years ago for him to go permanent at Boulden but I said 'Oh no I couldn't do that' and my husband then left it up to me because he knew that if he said he'd got to go that I wouldn't be happy so we just left it (Mrs Hudson)

I don't want her in hospital, that's the last thing I'd want her to do because in her state, that's the end. As you know they keep doping them up to keep them quiet and eventually it has the final effect. (Mr Hunter)

However, day care and short-term respite care in hospitals and homes were regularly utilised by many respondents with such facilities being identified as crucial in reducing carer stress (Henwood, 1998; Bauld et al, 2000). In accordance with this, some respondents were highly complimentary about these services, as the following quotes on care homes reveal:

To be exaggerating, it's a bit like utopia.....It's also good for her socially because she can talk to other people, which makes a hell of a difference. She can think about things for a week instead of being stuck between these four walls. (Mr Tumin)

The people at Bowl Hill have been very good, very helpful; they really are very nice people. You hear so many things about homes (Mrs Field).

Day care, which was received by nine households, was also mentioned:

With the three days that I have I'm able to catch up with things that I can't normally do because I have to follow her around making sure that she's OK (Mr Carson)

He goes out on Monday to physio. Wednesday, he goes to a club near Heeley baths and then on Friday he goes to Batemoor and Jordanthorpe centre. It just gives me that break in between and I have a few hours on my own. Plus the fact that when he's out I can do his washing and make sure his clothes are clean. (Mrs Halsey)

Others were less enthusiastic about day care and hospital or home-based respite care. This has been recognised by other research, which attributes this lack of enthusiasm due to such things as negative connotations of the workhouse and charity (Lewis, 1998). However, interviews revealed a further reason for this aversion: that is, the perceivedly poor standards of care provided in these settings. As Mr MacLellan and Mr Tunstall recounted on their experiences of private care home provision for their respective wives

They used to sit her in a chair with a television, a little one not much bigger than this and then just forget about her, leave her. Well if she sits there like that she'll probably try and get up and do something, she won't be watching telly all day long (Mr MacLellan)

They're only there for the money. Each room has a buzzer in to send for help, well as we sat there the buzzers went for five or ten minutes before anyone going, its no use complaining because from what you hear they're all alike but for £330 a week you hope for better. (Mr Hunter)

Consequently, rather being due to irrational and outdated cultural notions of the 'workhouse', the negative attitudes of many respondents towards hospitals and care homes could equally be seen as a rational response to realities of an inadequate service.

The Japanese look after their elders, not like we do. I've seen programmes on what they do for OAP's in Japan (Mr Phillips)

As Walker (1987) observes, welfare provision for older people in this country is notoriously under resourced and is both a symptom and a cause of their socially marginal status (chapter 1). This inadequacy is apparent not only in social welfare provision but also within the health service. For example, older people do not receive the same

aggressive health care treatment as the young and this is justified on the basis of economic priorities (Hilfiker, 1983). Such provision is not only inadequate but can also be inappropriate to the specific care needs of older people. For example, pressure for bed space in hospitals and the subsequent rapid discharge of patients can be incompatible with the nature of disability amongst older people and their subsequent tendency to take longer to recuperate than younger counterparts. This can in turn impact on the carer of the older person who is left to struggle at home with an older person who is not fully recovered. As Mr Tunstall said of his wife's recent hospital stay which he felt had been prematurely terminated:

I don't think they care too much. She very rarely had any attention except assistance to go to the toilet and occasionally they'd come round with the tablets, the usual taking of temperatures and blood pressure...it surprised me... they didn't pay attention to what she was like, they gave her a poor examination. She was not really fit to come out, especially coming out to be cared for by a ninety-year old fellow (Mr Tunstall)

Carers also spoke of the negative impact of institutional care on the well-being of the cared-for person due, for example, to environmental change in exacerbating their confusion and disorientation as well as generally poor standards of care (Parker, 1993; Levin et al, 1994). For example, Mr MacLellan spoke of the worsened physical state of his wife following hospital discharge:

Last time she was in hospital was five years ago and she will never go again, not unless it is imperative. Because last time she was in hospital it was for respite, to give me a break and that was for 10 days but each time she's been in hospital, every time she's come back she's been worse. Last time she had bedsores. Another time they turned her to one side and then forgot about her (Mr MacLellan)

Financial factors, especially the costs incurred to the household as a result of respite care stays were a further deterrent to the pursual of respite care admission, with such fees usually running into hundreds of pounds for most residential and nursing home care:

I did have her in a home for a fortnight while I went into hospital. It was a nice place and she was comfortable in there. It cost me £300 near enough for two weeks (Mr MacLellan)

Indeed, Mrs Flude highlighted the discrepancy in charging policy between health and social care, for those, such as her husband, who have been assessed as having special health care needs are able to enter respite care free of charge:

He used to go into a home for which we had to pay £200 a week, but now because he's been assessed as having special health needs, he goes in free of charge (Mrs Flude)

However, as Twigg and Atkin (1994) observe, unlike social service support, help from the health service is not allocated on the basis of the needs of carers and their material circumstances but on the degree of disability of the cared-for-person. For, while health provision is influenced by the medical model and concepts of physical pathology, social care provision is influenced by the wider context of the client. Moreover, despite the fact that health provision can offer important indirect support to carers, few actually receive this service and as Parker (1993) observes, its availability has progressively declined in the last ten years.

In addition to financial issues, the positive benefits gained from caring and the practical and emotional interdependency between carer and care recipient was a further factor in deterring the take up of respite care and day care (chapter 4). For example, Mr Dale described how he decided to withdraw his disabled son from his day centre following the death of his wife, not only because he was unhappy with the service that they provided but also because, his son would be of more practical use to him at home:

They were always short staffed and half the time he was just standing about. You see they're all disabled to different degrees. He's learnt more by not going and the advantage is that he's here with me all day and can help me out (Mr Dale)

Similarly, Mr MacLellan spoke of the emotional stress that he and his wife experienced as a result of respite care admission:

Well I know she's not happy when she goes in these places, she's happier at home and that's it. We've been married getting on for 60 years now and we cope

anyway...It's alright, respite, but the trouble is when she was in I used to go and see her nearly everyday. If I didn't she'd worry herself to death, it's a damn sight worse chasing backwards and forwards, she's better off at home (Mr MacLellan)

Consequently, as Langan et al (1996) found, many carers continue to fulfil a care-giving role after their spouse is moved into an institution and that care-giving stress may remain at a high level.

Domiciliary support

These findings suggest the need for flexible and affordable sources of formal provision, aiming to support the disabled person at home rather than remove them from it. Domiciliary support such as community-based professionals and sitting services seemed to go some way towards meeting this need, offering a flexible, regular and reliable source of support which was perceived as being preferable to day care and respite care (Twigg et al, 1990). For example some cited the help provided by community nurses, occupational therapists and social workers in supporting them at home:

They put a ramp in for us and they put double-glazing in for us. They send down a chiropodist because we can't get to the medical centre you see and they cut our toenails for us and things like that. Oh they've been very good the Social Services. I've got an address and a number to ring if anything goes wrong with the wheelchair like the brakes; they are here within the hour. When the tyre came off they came along and put a new tyre on, they have been very good, yes (Mrs Phillips)

As the majority of households had been recruited to the study via the home care service, most were in receipt of such a service for which they typically paid a subsidised fee of around £8 per week.

I pay for that willingly if it keeps them in a job. Because everything's cut down. I've got good backup (Mrs Halsey)

As Milne et al (2001) observe, the home care service is highly valued by those who receive it with Levin et al (1989) finding that this service could help to promote the mental health of carers. For example, the Joseph Rowntree Foundation (1998) has suggested the importance of 'low level' preventative services for older people such as

help with housework, gardening, laundry and home maintenance. These recommendations were upheld by many respondents in this sample for whom practical assistance in the home was their overwhelming priority.

However, while this service clearly provided respondents with much needed support and had the *potential* for flexibility, some complained that this flexibility was compromised. For example, Mr Caplow observed that home carers were no longer able to perform housework tasks:

Well the home care used to clean up and things like that but they don't do that anymore, they cut that out (Mr Caplow)

Mr Denis described how home carers were unable to cater to his special dietary requirements:

Home carers visit every day. But it's been changed because when they first came they were shopping for us but then men took over with the shopping and the carers still cooked but sometimes I have to do the cooking myself because of the kind of food I eat. You see, they can't manage that kind of food so I have to do it myself; I do my own cooking now. We eat sweet potatoes and yam and bananas. Only coloured people eat these things (Mr Denis)

Mrs Kincaid was unhappy about the inflexibility and unpredictability of home care visits:

Julie used to vacuum and tidy around but she should have been half an hour but she only stayed five minutes and she was being paid for half an hour. One came at eight and another came at half-past seven. I had trouble with her because you don't want to be up at half-past seven, especially if you've been up all night (Mrs Kincaid)

Finally, Mrs Flude observed how her privacy had been undermined by frequent visits by home carers:

You do sometimes feel that your home is not your own (Mrs Flude)

The inflexible practices of home care providers illustrate how contrary to the advocacy of flexible forms of support in the community and client empowerment, institutional practices can continue to prevail within a community setting and client choice is often simply limited to taking the service on offer or refusing it. As such, the needs of clients

and carers tend to be defined by ‘off the peg’ service solutions and interventions (Twigg and Atkin, 1994).

Carer support groups

Recent developments in community care have given rise to new forms of support for carers which recognise their potentially independent needs and their role as co-clients (Twigg and Atkin, 1994). Most notably carers support groups have become increasingly popular aiming to provide information, advice, mutual support and reassurance to informal carers (Argyle, 2002a; 2003a; 2003b) thus helping them to continue with their role. However, as Twigg et al (1990) observe, not all carers will want to join a support group. In accordance with this, only 3 carers in this sample were members of such a group, Mrs Reid, Mrs Hudson and Mrs Lipset. Most cited the practical demands of caring, as forming a barrier to membership. For due to their high involvement or ‘engulfment’ in their role (chapter 4), they were rarely able to envisage or pursue their own needs (Twigg and Atkin, 1994). As the following respondents said when asked if they were a member of such a group:

No, I can't leave her for long so I just don't bother (Mr MacLellan)

It's a waste of time; to me it is, yes. You see the thing is when you start joining a group or whatever; we get back to the routine. They say, right, half-past nine or ten o' clock the meeting starts. There's a time and a place. That's a luxury, which I'm afraid I've learned to do without. I can't do that because I don't know how she's going to be tomorrow or how she's going to be this afternoon (Mr Cicourel)

Well I'm not actually in a support group, no.. She doesn't like me to go out of the house for more than half an hour a day (Mr Davis).

They meet on a day when I can't go which is a Tuesday when I have no cover and to be perfectly honest with you, I find it very difficult to get myself into town. It's an effort when you're tired, it's a terrible effort. I know that sounds very negative

but when you're very exhausted, all you want to do is go to bed, I just want to sleep (Mrs Flude)

No. There's not much point because I can't really get out to go to one (Mrs Field)

In addition to the practical demands and subsequent 'restrictedness' of caring, possibly exacerbated by the disability or ill health of the carer themselves (chapter 3 and 4), attitudinal factors also likely deterred respondents from joining such groups. For, due to the interdependence of the caring relationship, many respondents did not perceive themselves as being carers (chapter 4). Moreover, their strongly held 'culture of coping' and subsequent propensity to put on a 'brave face' (chapter 4) was likely to further militate against membership of a carers group and the mutual self disclosure in a group setting that such membership implies. For, as Newman (2002) observes, the concept of a carer support group carries with it connotations of 'victimhood' which runs counter to the expressed perceptions of many carers in this sample. These issues serve to highlight a point initially alluded to in chapter two, that recent trends in user participation and 'self help' assume that users want to participate and that they are able to do so. As Miss Howard said:

You've got to get there and get a sitter and to be honest I don't think that sort of thing would appeal to me very much just going along to talk to other people about mutual problems (Miss Howard)

The commonly expressed needs of carers for practical assistance with practical problems and their corresponding rejection of more participatory forms of support throws into question the adequacy of the 'bottom up' approach to welfare in meeting their needs (chapter 1). Thus the focus of such an approach on the diversity and individuality of service users serves to overlook their collective needs such as those arising from material deprivation. As such it can in many ways be seen as a duplication of the long discredited pathologising modes of intervention favoured by the traditional social work and social administration approach (Wilding 1983). Moreover, the focus on the development of 'special provision' such as carers' support groups, which are run by and for service users,

assumes that carers will perceive themselves as such and will have the desire and ability to be a part of such groups. It also serves to ghettoise such services, reinforcing assumptions that such groups 'look after their own' (Ellis and Davis 1995).

Financial support

In view of the role of material deprivation in potentially exacerbating the demands on carers (chapter 3), access to financial, as well as service support, plays an important role in alleviating this deprivation and in compensating for the financial costs incurred as a result of this role (chapter 4). Relevant benefits include invalid care allowance, attendance allowance, mobility allowance, invalidity benefit and severe disablement allowance, as well as more general benefits such as income support. Invalid care allowance (ICA) is the only state benefit specifically designed for carers and aims to provide compensation for loss of employment. It is payable both to relatives and non-relatives (Glendinning and McLaughlin, 1993). However, as Twigg and Atkin (1994) observe, its impact is complicated by interactions with other forms of support and few carers can claim it. Indeed, none of the carers in this sample said they were in receipt of ICA, for due to its role in replacing lost earnings, those over the age of 65 have been ineligible to apply for it. While the government has recently removed this age barrier, older people with higher retirement pensions will still be ineligible due to 'overlapping' benefit rules (Baldwin, 1994).

Similar age based restrictions have been placed on the allocation of 'direct payments'. These were introduced under the Community Care Direct Payments Act 1996 and gave local authorities the power to make cash payments to certain individuals to enable them to purchase care for themselves. As such, they are potentially available to individuals who fit the definition of disability as cited in the National Assistance Act (1948) including those with physical disability, learning disability, mental ill health, sight or hearing impaired and older people with physical frailties. However, until February 2000, such payments were not available to those who become disabled in older age. While this availability has now been broadened by local authorities to include older people, take-up has been minimal with only 209 older people in the country accessing this scheme in

2001 (Leece, 2001). Moreover, Leece (2001) found that while 80 per cent of local authorities have started to make direct payments available to younger disabled service users, in 2001, only 24 local authorities had schemes which included older people. Even when local authorities have made this scheme more widely available, cost ceilings are applied to individual packages of care (Kestenbaum, 1999). These ceilings are generally lower for older people who therefore have less money to spend than their younger disabled counterparts. Older people are also disadvantaged by the independent living fund (ILF). This is a joint care package with the local authority worth up to £625 a week, but is only available to younger people with a disability with those aged over 65 being ineligible to apply. This widespread practice in treating older people differently and less well than their younger counterparts, runs counter to rhetoric on anti-discriminatory practice and can be seen as implicitly reflecting pathological perceptions of ageing. That is, in accordance with the social disengagement theory, older people do not have the right to lead active and independent lives and are therefore not in need of benefits which would help to facilitate this independence

A more commonly claimed benefit, which was received by 25 respondent households (table 3.4), is attendance allowance, which is a tax-free weekly benefit for people aged 65 or over who need help with personal care because of illness or disability. For people to get the allowance, they must normally have needed help with personal care for six months, although there are special rules for those who have a terminal illness. This allowance has two rates depending on the level of assistance given by the carer and is not dependent on National Insurance contributions, or effected by any savings or income. A further nine respondent households were in receipt of disability living allowance. This is an equivalent form of benefit to attendance allowance but one for which only those under 65 are eligible to apply. Like attendance allowance, this benefit is designed to compensate disabled people for the extra costs incurred as a result of their disability (Nissel and Bonnerjea, 1982). However, due to the ageist nature of the benefits system, DLA is considerably more generous than AA, incorporating as it does a low rate which is available to those with only minor disabilities and incorporating a mobility as well as a

care component. Moreover, unlike AA, DLA does not require that applicants have been in need of care for at least 6 months before the application is made.

In summary, although the social security system is meant to support carers, levels of support are extremely low (Glendinning, 1992). Not only are available benefits meagre but also the take-up rates of such benefits are also low (McLaughlin, 1991). Graham (1984) attributes this to potential claimants' lack of knowledge of the benefits system and their eligibility for such benefits. This view was echoed by respondents who, as was the case with formal support, found the benefits system confusing and difficult to access:

Those (benefit) forms are diabolical to fill in (Mrs Halsey)

Others spoke of the perceived unfairness in the allocation of benefits and allowances:

That attendance allowance, I think that's not right, well there's no means- test or anything I know of a millionaire that was drawing attendance allowance (Mr Hunter)

Her next door she gets disability living allowance. She's up to date with cars, she's got a T reg and she also works but that's her business (Mr Hall)

We've always wondered why some people get disability allowance and yet he's a lot worse and he's never had it (Mrs Taylor).

Some people never do a days work in their lives, I don't know how they get away with it (Mr Phillips)

Moreover, due to their cautious approach to money and attitudes of independence (chapters 3 and 4) most respondents tended not to perceive themselves to be 'poor' or in need of welfare benefits. For example, it was shown in chapter three that Mr MacLellan decided not to apply for the income support to which he was entitled as he felt that he could manage on his existing low income. Similar attitudes of independence were expressed by many other respondents:

I have paid my taxes all my life. I try to be independent...what I've worked for all my life that's my own business, such as my occupational pension. I'm pleased that I've got that independence from the state" (Mr Dale)

GAINING ACCESS

Only a small minority of older people are in receipt of formal support of any kind. This is especially the case with older carers who experience difficulty in gaining access to community services as they tend to be targetted at older people living alone (Milne et al, 2001). Thus the OPCS (1983) found that support services were received by only 4 per cent of older people living with a spouse. Problems of access have been exacerbated by the privatisation of respite care services and the consumerisation of the welfare market due to older peoples inability or unwillingness to pay for such services (chapter 3). This unwillingness may not simply be due to lack of money but also to 'habits of the heart' and a subsequent reluctance to pay for things which have traditionally been provided free of charge by the health and social welfare services (Baldock and Ungerson, 1994). In addition, the inadequate resourcing of service provision for older people has exacerbated their dependence on informal sources of care rather than alleviated it with the state being committed to a practice whereby the bulk of support for older people is provided by such sources (chapter 1).

Nobody sort of helps you into this situation, if a woman's expecting a baby she gets all sorts of help in advance, she gets ante natal care she also gets advice on how to look after a young baby. Nobody tells you how to look after an elderly person, nobody tells you how to lift them out of a chair, nobody tells you about the best way to go about bathing them, you know, you know you've got to do this for yourself. Nobody tells you initially where to get a wheelchair, you've got to make all the running, in a sense you've got to do this and find out for yourself and if you're the only person, that's not always so easy. (Miss Howard)

Disempowerment in the context of service diversity

These difficulties in access were compounded by the fragmentation of formal support provision which has taken place as a result of welfare pluralism which led to confusion

amongst carers over what help was available to them and how it could be obtained (chapter 3). For example, research has shown that the majority of carers of people with dementia are unaware of the services, which are available to them, and many provide care for long periods before they receive any help (Philp et al, 1995; Moriarty and Webb, 2000). Moreover, as Stanley (1999) observes, in addition to money (chapter 3), a powerful voice, high expectations and information needed to enter the welfare market and articulate one's needs. Consequently, the words 'struggle' and 'fight' were used by a few respondents when recounting the process of gaining access:

We've got a stair-lift, which the social service put in after a struggle (Mrs Gibbons)

Whatever I have got I have had to fight for. (Mrs Halsey)

In the beginning I really had to struggle, I didn't know who to turn to. My son used to have to pick him up when he fell over but now I'd know to call an ambulance. It sounds obvious but when you've never experienced it before..(Mrs Flude)

Such lack of information also raises concerns about the ability of carers to make informed choices about the most appropriate solutions for themselves and those for whom they care:

I have a very short memory and I get confused about what services are available (Mrs Flude)

For example, as Mr Cicourel described his attempts to obtain a home sitting service for his wife who had multiple sclerosis:

Somebody came, just like you, sat down, interviewed me and she said, how many times a week do you want help and I said 'whatever' and she said, how about a couple of times a week and I said yes that would be great. A week after she rang and said I'm ever so sorry but I'm afraid that you don't qualify because your wife isn't old enough.(Mr Cicourel).

Certain people, you think they look all right and then they get these free passes without having to pay for anything. He doesn't want what he's not entitled to, but if he's entitled to it, he's a right to get it, that's what bothering him" (Mrs Taylor)

This confusion promoted a subsequent reliance on relevant professionals for guidance, undermining the principles of empowerment upon which welfare pluralism was based. For example, Mrs Flude went on to describe how, after remaining unsupported for several years, she was forced to turn to her GP and then a social worker to help to guide her through the maze of formal provision:

In the end I went round to the practice (GP) and beat my fist on the desk...the key to the whole thing is a social worker, these things don't come to you other than through a social worker. That's the key, to have a social worker who is like, your ambassador, your mentor really, without a social worker I'd be in the dark

Similarly Mr Millett claimed that he felt he lacked control over where his disabled daughter would be placed when he was no longer able to look after her at home:

It's difficult for the client to have any say in where they go, I mean my daughter wants to live with another family. They still have council hostels in Sheffield but with some the management has been transferred to a housing association. There are lots of private homes but even with private homes you have to have council funding but unfortunately she won't be allocated one until I die. I'm quite happy to carry on caring but who is to say what will happen when my health deteriorates.(Mr Millett)

Moreover, initial access to formal support was rarely initiated by the older person themselves but had commonly been initiated after a crisis situation by welfare professionals, often after hospital admission:

I think how it came about was me having a bad heart. They asked me all these questions. I said my wife has to see to me the best she can and I see to her. It snowballed from there. They have welfare workers in hospital and they came to see me, they thought it was necessary for this to happen (Mr Hall)

Yes, the care workers and social worker started through me having to go into hospital for an operation in June 1997.... Then when I came back the social workers came and Edna was very ill so I applied for more social help. The doctor said I tell you what I'll do, I'll let her come home and we'll have to see how you get on so I said alright (Mr Tumin)

For others, access had been initiated by relatives, possibly with a view to alleviating the potential burden on themselves:

It was my daughter. My daughter said I needed to do something about it, she said you're not going to manage. Just before Christmas I went down to the doctor. I thought I had flu but I had to have a pacemaker fitted. I've got diabetes as well, so it pushed things along and my daughter said I can't look after her (his wife). So they came to assess her and it started straight away. (Mr Carson)

My daughter said, 'Look dad, you're 90 years old and you've never had a bit of help, it's time you did have' (Mr Dale)

Age based specificity

In addition to barriers of service inadequacy and confusion, respondents own self-perceptions and attitudes of independence could be seen to form a further barrier to accessing formal support provision. For example, the fact that many older people supporting others do not perceive themselves as carers or in need of 'carer relief' (chapter 4) may mean that supportive services will continue to pass them by. As such, it was seen in previous chapters that the appearance of being able to cope was crucial in maintaining older people's sense of self worth. Baldock et al (2001) suggest that this attitude is reflected in their view towards support provision with the receipt of such provision being regarded as an admission of defeat in their battle against disability and dependence:

To use a service was to lose this battle or at least it was an admission of a weakness of spirit and resolve. The possibility of getting and using services or going to day centres confirmed for many their arrival at unwanted destinations in the downhill journey of ageing. So agreeing to a service was for most of our sample incompatible with their personal project to fight, delay or even deny (Baldock et al, 2001: 13)

Consequently, respondents in the sample often perceived formal provision in a negative light and as a potential threat to their independence, displaying a corresponding tendency to underplay their extent of disability and subsequent need for help:

I'm not going into a home, don't get me wrong, they're marvellous places but I wouldn't like to give my home up to go into a home while ever I'm on my feet. While ever I'm on my feet, I'll carry on. Neither of us want to go into a home they take your independence off you don't they. (Mrs Halsey)

In view of such attitudes, due to the fact that access to respondents in this sample was negotiated via welfare agencies, it is probable that their experiences were not typical of those of older carers as a whole who are likely to be even less well endowed with external sources of support

This tendency for older people to struggle in adversity and their ambivalent views towards formal support has important implications for welfare trends in consumerised and pluralistic services. For example, their tendency to pursue formal support only when a crisis situation has been reached is likely to undermine their inclination and ability to 'shop around' for these services. This is compounded by the nature of disability in older age, for unlike most younger people with a disability who usually have long term and relatively stable support needs, the onset of disability and ill health in older age is often sudden. Older peoples 'culture of coping' also has implications for client-centred assessments and the accuracy of information gleaned from these (chapter 4). For example, not only is the Attendance Allowance application form very time consuming to fill in but it also requires potential recipients to be open and explicit about their limitations and subsequent need for help. In the light of these observations, Barnes (1997) suggests that greater periods of time need to be spent with older people, than with younger people, explaining the system and resolving their fears and that social workers should not take initial certainty as an automatic refusal. This theme is elaborated by Baldock et al (2001) who controversially suggest that older people, particularly after the sudden onset of disability or illness, are unable to accurately judge their own needs (chapter 4). Consequently they maintain that service providers should aim to overcome older people's innate independence and reluctance to ask for help through persuasion and

the prompt and gradual input of appropriate forms of intervention. In addition, it is suggested that assessment must be an ongoing process or regularly updated as older people gradually come to terms with their need for service input (Baldock and Ungerson, 1994). If this is achieved, recipients may go on to experience improvements in their social and psychological well-being, in spite of their initial reservations.

Case study 5.2: Mr Tumin – the pressurised welfare recipient

Mr Tumin was an 84-year-old man who had been looking after his wife since she first became ill in 1996, suffering as she does from a variety of problems including vertigo, hardening arteries, occasional confusion and minor strokes. Mr Tumin himself also had health problems including osteo-arthritis, padgits disease and mobility impairment as a result of a hip replacement. He first came into contact with formal provision in 1997 when he had to go into hospital and needed support for his wife while he was away. This led him to be allocated a social worker who followed up his hospital discharge and persuaded him to accept home care and respite care for his wife. In subsequent years, Mrs Tumin has received increased amounts of support and now goes in to respite care every five weeks about which Mr Tumin was highly complementary.

“I’ll be quite candid, its luxury. There’s a single bedroom on suite with a television in it, you can’t get more luxurious than that and the food is absolutely fantastic. She says it’s like a first class hotel for the food. The carers are out of this world and so are the medical staff. I said, so you’ll come back here again? And she said, oh yes, she wouldn’t hesitate”.

Consequently, in spite of these initial ‘pressure tactics’, Mr Tumin was very pleased with the services he subsequently received, as he said about his social worker:

“Oh she’s fantastic, really fantastic. I can’t praise her enough. I only have to get on the phone and she’s here, she comes of her own accord sometimes”

The effectiveness of these recommendations is well illustrated by a few cases in the sample, for example although Mrs Halsey felt that in the initial stages of domiciliary service input, providers were ‘taking over’ she went on to value the service she received

Well, they wanted to move in a single bed in place of our double bed, everybody was taking over. I said, me and Brian have been married all these years and you’re not moving us out of a bedroom together, we’ve always slept in the same bed side by side.... But once I said I needed more help, I got it, don’t get me wrong, especially putting him to bed at night, he got too heavy for me and I couldn’t shift him so they undress him and put him to bed for me. (Mrs Halsey)

Similar experiences were voiced by Mr Tumin, who was initially reluctant to accept help in the care of his wife (case study 5.2):

They were getting on to me and I was laying the law down as I saw it. There was Julie my social worker, two more ladies and a nurse I think she was a district nurse and then the two carers so I had four women I had no chance had I! (Mr Tumin)

Nevertheless, in spite of the merits of the above suggestions (Baldock et al, 2001), the generally low priority given to services for older people throw doubt over the willingness of local authorities to implement them. For not only do they run counter to the rhetoric of ‘client centred’ assessments deeply ingrained within the policies and procedures of social welfare. They are also incompatible with the wider context of resource constraint, especially with regard to older people, within which such services operate. For example, service providers repeatedly emphasise that, because of this resource constraint, they do not, in general, seek out carers and respond only to those who are assertive and who push themselves forward (Twigg and Atkin, 1994). Moreover, as the Marxist perspective suggests (chapter 1), welfare professionals such as social workers, do not simply autonomously and altruistically respond to the needs of their clients. For their actions are limited by the wider context of resource constraint in which they operate. While, in some cases, it may be possible to partially transcend these constraints through the provision of prompt, sensitive and persuasive intervention, such cases are likely to be exceptional with pressure of work and inadequate resourcing rendering such intervention at worst impossible and at best, very inconvenient (chapter 6). Moreover, if prompt and sensitive intervention is to be achieved, prompt access must be gained to the client in need of such intervention. However, as has been suggested, this is often not possible, due to older people’s unwillingness to seek help until crisis has been reached. In the light of these constraints on the actions of welfare providers, researchers and policy makers should shift their focus from the values and behavioural norms of welfare professionals and officials. Instead more attention should be paid, not only to wider issues of resourcing but also to the cultural needs and age specific requirements of the older people who are in need of such resources. Thus, as Baldock (1999) observes on the analytical tradition of social policy:

Rarely is much said about the nature of the wider culture into which policies are delivered and why that responds in varied ways. This is partly because this research tradition developed from within the policy sciences and therefore has an institutional focus, and partly because researchers have found ways to study and describe the practices and culture of bureaucrats and professionals but not to account for the behaviour of consumers (Baldock, 1999: 464)

Consequently, in spite of post-modern and neo liberal rhetoric to cultural sensitivity and eclecticism (chapter 1) these age specific requirements have not been fully recognised or responded to.

CONCLUSION

Contrary to postmodernist portrayals of the increasingly individualistic nature of informal care provision (chapter 1), the first part of this chapter showed the way in which, like the co-resident caring role of respondents, their access to informal networks of help was, to some degree, socially structured. This was evidenced, for example, in the apparent hierarchy in the identity of informal care providers, while the potential availability of such carers was undermined by wider social trends, such as increasing levels of geographical mobility and the increasing entry of women into the workforce. Similarly, material factors led to some diversity in the experiences of respondents with social marginality, instrumentalisation in caring relationships and adverse environmental factors exacerbating the isolation of poorer respondents from wider networks of support. However, non-material, age specific factors also had an influence on access to such support. For example, due to the increased incidence of disability and ill health amongst their contemporaries and the physical limitations arising from this, practical assistance from same generation sources such as siblings as relatively rare. Moreover, attitudes of self-reliance and cultures of coping rendered respondents reluctant to turn to informal sources of help. This role of age specific factors in mediating the influence of material factors helps to explain the fact that, on one hand, material expedience strengthened the bonds between carer and care recipient (chapter 3 and 4), while, on the other hand, access to wider networks of support was potentially undermined by such expedience. This in turn serves to highlight the inadequacy of structural perspectives such as situational constraints theories, failing as they do to fully explain these diverse responses to similar material situations.

This combined influence of material issues, attitudes and physical pathology also affected respondents' access to formal sources of support. Thus on a material level, poor resourcing and means testing formed an important barrier to accessing formal support provision with the relative poverty and material interdependency of many respondent households rendering them unwilling or unable to access such provision. Moreover, such services were not always compatible to the needs and preferences of the carer and cared for person. For example direct payment schemes and the emergence of pluralistic welfare services may be incompatible to the requirements of older people for whom the onset of disability and ill health tends to be sudden, leaving them uninclined to 'shop around' for services or set up complex direct payment packages. Neither do rapid discharge policies always suit the needs of older people who tend to recuperate at a slower rate than the young. While the physical demands of caring are also likely to form a barrier to the user led and participatory services emerging in recent years with practical help with practical problems rather than user led involvement being the overwhelming priority for carers in this sample. Finally, with regard to attitudinal factors, the wish for independence, the positive benefits of caring and the culturally based rejection of welfare consumerism due to habits of the heart (Baldock and Ungerson, 1994) will form a further barrier to accessing formal provision. It will be the purpose of the next chapter, '*Constraint, Culture and Caring*', to summarise the influence of material resources, culture and physical pathology in the lives of older carers as well as to examine some of the implications of these findings for policy, practice and research