

# Three Years at Home: The Final Report of the Longitudinal Study of Community Support Services and Their Users

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## 8 The Use of Formal Services

Given that all participants in the sample had initially been referred to the Broadleigh Aged Care Assessment Team which provided them with an accurate assessment of their needs for support and, where appropriate, referred them onward to community services, it could be expected that the use of community services by participants would be relatively high in comparison with other recipients of support in the home who had not been referred to the Assessment Team. With few exceptions, however, participants made only modest use of services while they remained at home.

In this section we address two of the research questions with which we commenced. What resources are provided to assist those who remain at home? What is the relative significance of formal and informal sources of support in the home?

To examine the contribution of community support services to participants who remained at home we present information, as in the Section 7, using a 'before and after' comparison which focuses on those at home at Stages 1 and 4. In some instances data collected at other stages of the study are also presented, and the use of services by those who remained at home compared with that of participants admitted to residential care. Following a general overview of service use amongst the sample of participants at the aggregate level is an examination of the use of day care services. The section concludes with a discussion of three case studies which explores the personal history of service use of individual participants, drawing on the perspectives of both consumers and service providers.

As there is no single measure which successfully captures the full complexity of the use of community support services by people living in their own homes, information provided by participants or their caregivers is presented here using a number of different measures. The data is based on self reports provided by participants and their caregivers. Although it was not possible to corroborate the essentially subjective information provided by users and caregivers against service records, as this would have breached the services' confidentiality provisions, every attempt has been made to ensure that the information provided is accurate. Inconsistencies between sources have been reviewed and data included in the study only when our doubts have been removed about its validity.

### 8.1 Evidence of Service Use

The regular receipt of different services at different stages of the study, reported by those still at home and those admitted to residential care, is presented in Table 8.1. A simple and relatively basic measure, 'reported service use by participants' is employed. This indicates simply whether a service was received regularly or not at the time of the interviews.

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**Table 8.1: Receipt of Community Support Services by Outcome: Stages 1 and 4**

Service Type	Outcome		
	At Home	At Home	Admitted to
	Stage 1	Stage 4	Residential Care
Percentage of participants using service			
<b>HACC funded services</b>			
Home Care	46	48	41
Home Nursing	11	24	23
Meals on Wheels	6	8	32
Day Care	7	20	9
Community Shopping	7	12	0
In-home respite	6	8	0
Other respite	4	4	5
Community Options	n.a.	12	14
Assessment Team Monitoring	72	28	41
<b>All Participants</b>			
Percentage	100	100	100
Number	54	25	22
<b>Other services used at home by participants</b>			
<ul style="list-style-type: none"><li>• Colostomy Association</li><li>• Community Aid and Information</li><li>• Community Health Centre,</li><li>• Community transport</li><li>• Guardianship Board</li><li>• Home handyman</li><li>• Home Maintenance and Modification services</li><li>• Hydrotherapy/other outpatient care</li><li>• Italian Welfare (COASIT)</li><li>• Legacy (voluntary org. for families of veterans)</li><li>• Library Service</li><li>• Oxygen cylinders (prov. by Dept. of Veterans Affairs)</li><li>• P.A.D.P. Scheme (a public scheme for the supply of disability aids and equipment)</li><li>• Podiatry</li><li>• Private gardener</li><li>• Private hairdresser</li><li>• Private house cleaner</li><li>• Private physiotherapy</li><li>• Public Dental Clinic</li><li>• Royal Blind Society</li><li>• Vital Call (mobile personal alarm system)</li></ul>			
<p>Note: a) These figures refer to services the participants reported as being received at the time of the interview, or are the best available prior to the admission of participants to nursing homes or hospitals.</p>			

Just under half the participants at home were assisted by a staff member of the Home Care Service of New South Wales, making it the most widely used service reported by participants. Use of other HACC funded services, including home nursing, Meals on Wheels and day care increased over the three years of the study. Nonetheless, these services were used by no more than a quarter of those who remained at home.

A wide range of other services, many of which were private and not part of the HACC program, were also used by individual participants. These were in addition to other general community services such as the normal utility services (telephone, electricity, gas, post and garbage) used by participants and the general population but not shown in the table. The use and significance of these services, which was an incidental rather than a major research topic in this study, is clearly a topic worthy of detailed attention in its own right in further research.

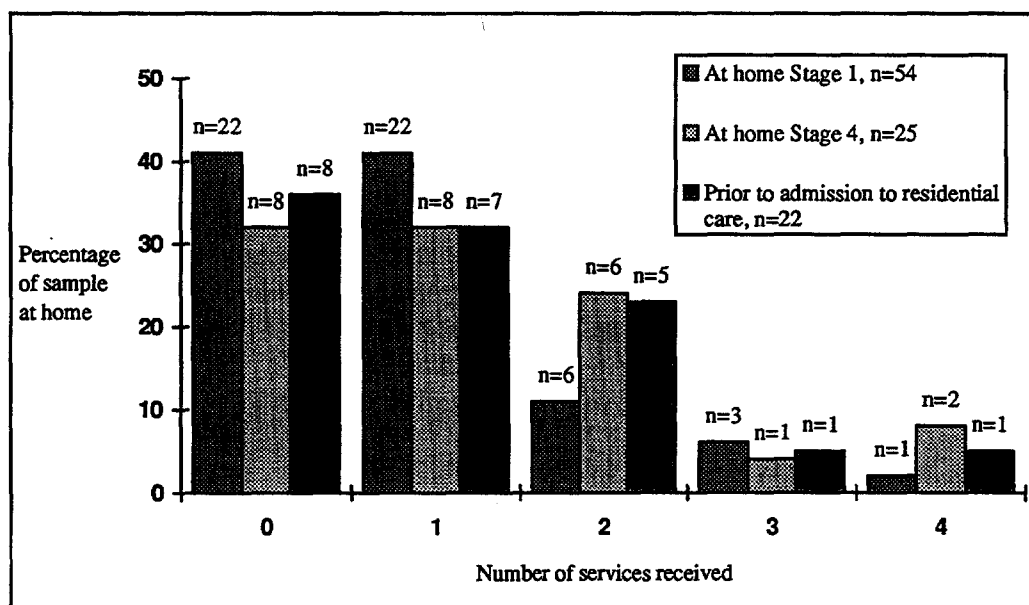
A more detailed picture of the extent of use of the main HACC services by participants who remained at home is presented in Figure 8.1. Confirming the pattern of a low level of service use already evident, this shows that the majority of participants at home received either no HACC services whatsoever or were reliant on the assistance provided by only one service. There was, however, some increase in the proportion of participants receiving two or more services over the three years of the study, an increase which was also reflected in the pattern of service use evident amongst those who were admitted to residential care. Only a small minority of participants at home received anything resembling a comprehensive range of assistance, which required help from several agencies at once.

There was little or no evidence of difference in the services received by those who remained at home and those admitted to residential care. The most obvious exception to this tendency was the Meals on Wheels service, responsible for providing cooked meals at home to people unable to cook for themselves, reflecting the relatively high rate of admission of participants living alone. This was used by 32 per cent of participants (seven of the 22) admitted to residential care, but by only eight per cent (two of 25 participants) who remained at home after three years. In contrast, other services, notably day care, were used much less by those subsequently admitted to residential care than by those who remained at home over the full period.

The measures of service use discussed so far refer simply to the number of services used and do not distinguish the frequency or amount of assistance received by individuals. Information available on the frequency of the receipt of home care,

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**Figure 8.1: Number of HACC Services<sup>(a)</sup> Used by Participants Remaining at Home: Stages 1 and 4 and Prior to Admission to Residential Care**



Note: a) The five major HACC services included in this table are Home Care, Home Nursing, Meals on Wheels, Community Shopping, Day Care and Respite, provided either in the home or in other locations. There were no participants who reported using more than four of these service types.

home nursing and day care services,<sup>28</sup> the most commonly used of the formal community support services, shows that, with few exceptions, services were used only at a relatively low level of intensity (see Table 8.2). Most recipients of Home Care received assistance only once a week or once a fortnight, although there were a few individuals who received help several times a week (six to nine visits a fortnight), and some who received help on a daily basis (10 or more visits a fortnight). This occurred more commonly amongst participants at the end of the three years than at the beginning and was slightly more common amongst those admitted to residential care than amongst those who remained at home. There is also some evidence of a more intensive pattern of use of home nursing and day care

28 For services provided to all clients in a standard way, such as Meals on Wheels, which is provided five times a week to virtually all recipients, and community shopping, organised once a fortnight, there is little individual variation in their intensity of usage possible. Other services, such as respite care, in contrast, tend to be used only infrequently and comparison of the frequency of their use is therefore not particularly revealing.



The extent of the use of day care services is shown in Table 8.3. At the time of the initial assessment of clients by members of the Aged Care Assessment Team, day care was recommended as appropriate for 20 of the 60 clients, (33 per cent of the total sample). A high proportion of clients, however, either did not wish to attend or, having attended once or twice, did not continue to attend. As a result, only three people (five per cent of the sample) were actually attending day care eight months later, the time of the first round of interviews for the study.<sup>29</sup> The number of participants attending day care centres actually increased from three to five over the three year period of the study. This was despite the fact that two of the three people originally attending day care were admitted to residential care or died, along with a high proportion of the remainder of the sample. As a result of both the increasing number of users attending day care and the overall decrease in the numbers of users at home, the proportion of participants at home attending day care centres actually increased to 20 per cent of the total of those who remained at home the full three years.

A feature of this pattern of usage is that after three years, the only participants attending day care were people with a physical condition living with others. None of those living alone who remained at home after three years attended. Five of the 11 people living with others who remained at home after three years (45 per cent of the group) attended day care at least once a week. In two cases attendance was twice a week. There is no other single feature which marked attenders off from non-attenders in the study. No attendance was noted in the final stage of the study by those living alone, either those with physical conditions or those with cognitive or behavioural conditions. Neither did any of those with cognitive or behavioural conditions living with others attend. In the period immediately following the referral of clients to the ACAT, two clients with cognitive or behavioural problems (one living alone and one with others) had attended day care, each for two days a week. Unfortunately, they were both subsequently admitted to nursing homes after having been supported at home for just over a year. Given the emphasis placed by service coordinators on providing day care to those who are socially isolated, we had expected a higher proportion of users living on their own to attend. However the evidence is that day care was operating over the long term in a way which assisted those living with others, providing some short term respite to caregivers and social interaction for those attending. There was no evidence, however, that day care was effective in overcoming the social isolation faced by participants living on their own.

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29 One other had attended day care for a short time, but participation was discontinued following an improvement in his health as he no longer met the conditions of eligibility for the palliative care day centre to which he had belonged. Another person had commenced day care but was admitted to hospital and was unable to continue.

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**Table 8.3: Attendance at Day Care and the Residential Outcome of Support at Home: At Initial Assessment and Stages 1 and 4.**

Characteristics of Participants	ACAT Assessment Day Care Recommended	Stage 1		Stage 4	
		Attending Day Care	Total at Home	Attending Day Care	Total at Home
Number of Participants					
<b>Living Alone</b>					
A: Cognitive/behavioural problems	3	1	6	-	1
B: Physical problems	4	-	20	-	9
<b>Living with Others</b>					
C: Cognitive/behavioural problems	6	1	10	-	4
D: Physical problems	7	1	17	5	11
<b>All participants</b>					
Number	20	3	53	5	25
Percentage	33	7	100	20	100

The limited use of day care by those with cognitive or behavioural problems, particularly those living with others, must also be regarded as at least partly a result of the inadequate arrangements for support at home. The fact that day care was recommended for six of the 11 participants with cognitive/behavioural problems living with others but only finally used by one, as all others refused to attend, suggests that problems of 'consumer resistance' might also be involved. The failure of participants with physical problems living alone to use day care services also suggests that the existing services may not be particularly suitable or enticing for this group. Many of those who lived on their own were not housebound and were able to participate in social clubs and activities.

### 8.3 The Balance of Formal and Informal Care

The evidence from the study suggests that the bulk of care at home was provided by informal caregivers rather than services. The significance of the help provided by caregivers in comparison with that provided by community support services can be seen in Figures 8.2 A and B. This presents information collected respectively, from 45 participants (including some who were subsequently admitted to residential care) covering their time at home in the first 16 months since their initial referral,



and from the 24 participants still at home after three years. In all activities except bathing, the proportion of participants assisted by caregivers far exceeded the proportion assisted by services.

In the second year of the study, all assistance provided by services for shopping and cooking, and a high proportion of the assistance provided by services for personal care activities as bathing and dressing actually went to participants with physical problems who did not have a co-residential caregiver to assist them. In other activities, such as shopping and cooking which did not require such intensive intervention, the proportion of people assisted by services was considerably lower, with most participants relying on assistance provided by informal caregivers. This suggests that service delivery emphasising personal care was being targeted at those who live alone, while other activities which can be managed more successfully by a non-resident caregiver, were undertaken predominantly by informal caregivers.

Although the respective contributions of formal services and informal caregivers remained relatively stable over the period of the study, the pattern of service receipt changed. At the end of the three years participants living on their own who required help with personal care had either been admitted to residential care or had died. Assistance with personal care provided by services went exclusively to assist high dependency participants living with others. Assistance with cooking and shopping continued to be provided largely by informal caregivers and other individuals from the participants' support network. For both activities, assistance was provided to an equal number of participants living on their own and those living with others.

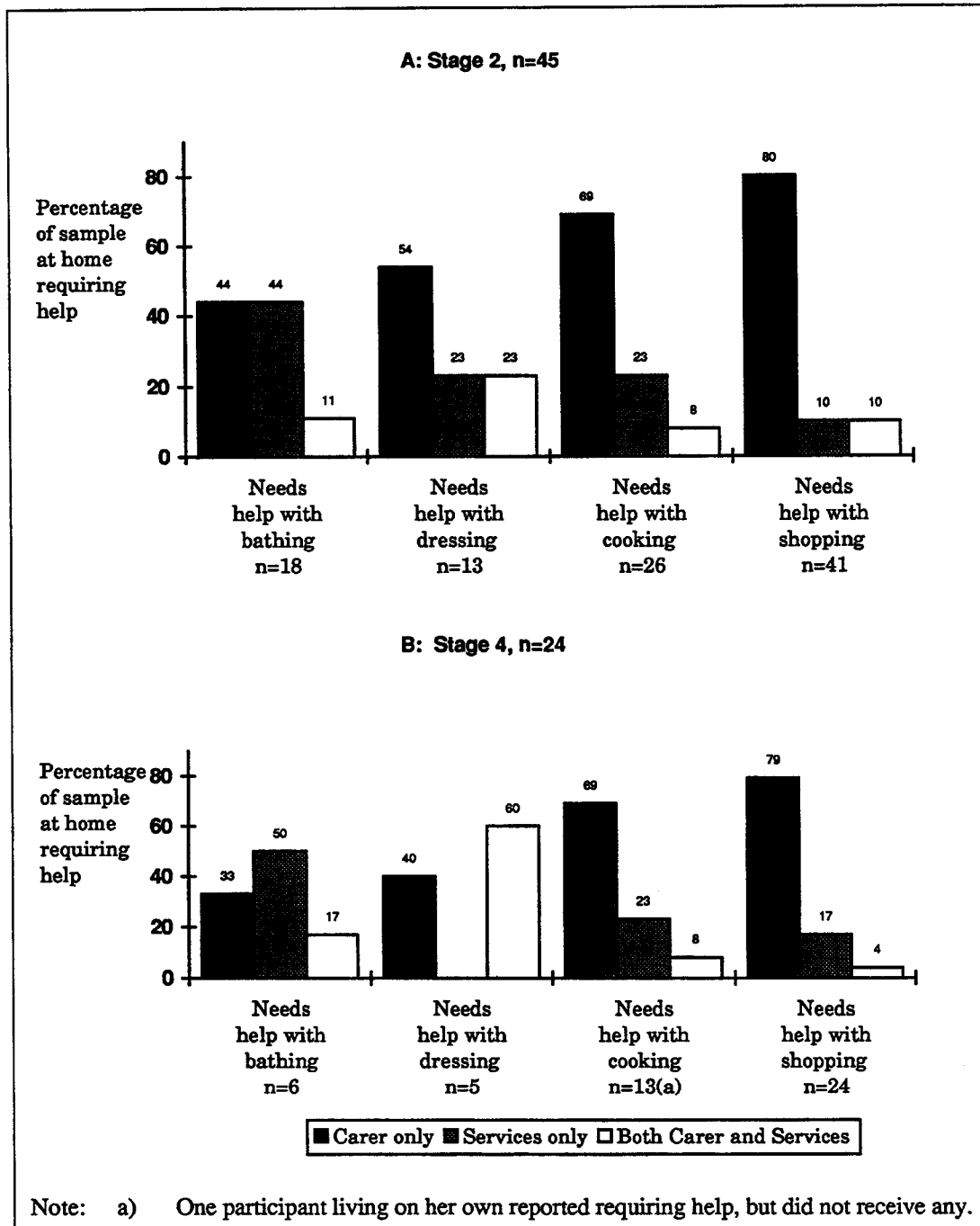
## **8.4 Personal Histories of Service Use**

To better understand the pattern of service use amongst participants, a qualitative research methodology was employed. Since it was not possible to gain access to comprehensive records of service provision for reasons of confidentiality, nor to discuss details of the use of particular services by known individuals with service providers, we conducted interviews with leading service providers, using three anonymised case studies drawn from the research with participants. Details of the methodology are provided in Section 2 of this report.

Although each case study portrayed the unique features of the individual case, it was selected as representative of a broader pattern of social support and service use amongst participants. We discuss each case study in turn, drawing on the explanations of both participants and service providers to explore the factors associated with the use and non-use of services more fully.

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**Figure 8.2: Main Source of Assistance for Participants Requiring Help with Selected Activities at Home: Stages 2 and 4**



### Case Study One

The first case study discussed with service coordinators concerned a woman known by the pseudonym Mrs Olive Osborne who remained at home with virtually no help from services, despite needing ongoing assistance. The case illustrates one way in which client and caregivers may exist almost autonomously, outside the sphere of influence of services.

Mrs Osborne turned 75 in January 1990, a month after she was referred to the Broadleigh Aged Care Assessment Team. She appeared frail and reported a number of debilitating health problems: diabetes; hearing loss; sleep disturbance; anxiety; heart disease; peptic ulcer; chronic obstructive airways disease; osteoporosis, incontinence and mobility problems. She had also suffered two heart attacks in 1989 and 1990. At the initial assessment Mrs Osborne had difficulty coping at home due to her loss of mobility. Inside the home she required two walking sticks and could move only with difficulty. Leaving the home without assistance was impossible. She regained some of her mobility after attendance at a mobility group organised by the Broadleigh ACAT, and at the time of the first round of interviews reported that she now visited the RSL club twice a week with assistance from her housemate and caregiver, Charlie. Her only other outings were a fortnightly visit to the doctor.

Over the next two and a half years Mrs Osborne's health declined markedly. In the final stage of interviewing she had just returned home from her third visit to the hospital in six months. Two of these episodes were for what she described as diabetic attacks. She also reported that she had a 'mini stroke' and a suspected heart attack. Although she seemed more alert than on previous visits and reported that her appetite and sleeping pattern had improved, her walking had deteriorated and she now needed a walking frame. She had also developed rheumatism in her arm, and complained of continual pain.

Mrs Olive Osborne shared a rented ground floor flat with her friend and main caregiver, Charlie. Charlie (who preferred to be called simply by his first name) was an energetic and fit man in his early 70s. He recently suffered a blackout which he said may have been caused by his slipped disk. Otherwise he felt his health was fair.

Mrs Osborne reported that she relied on Charlie to help her get in and out of the bath, and to assist her with urinary incontinence and occasionally, with incidents of bowel

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incontinence. He also did most of the cooking, cleaning and laundry, although Mrs Osborne said she still did her own personal washing. Charlie also organised her banking and her medication, took care of any repairs or maintenance required at home and always accompanied her when she went out.

The only assistance from community support services received by Mrs Osborne over the three years of the study were attendance at the mobility group organised by the ACAT for eight weeks in 1990 and, from mid-1992, weekly treatment for rheumatism from a physiotherapist from the Community Health Centre.

Although Olive Osborne had high levels of disability she did not use any community support services on a regular basis. The only additional assistance that she and Charlie said they would have liked was for her to attend a day group. After a few unsuccessful attempts to contact support services for advice on gaining entry to a day group, however, they decided not to pursue it.

Almost all service managers discussing the case expressed indignation that a situation which they considered to be 'inadequate' and even 'dangerous' could have been allowed to continue for so long. As the Director of one of the Municipal Home Nursing Services said, 'it simply should not happen'. But despite her indignation there was also a recognition, borne of experience, that such situations were common.

All service staff interviewed said that it seemed as if Mrs Osborne had a good chance of remaining at home, although she needed regular assistance to support her. Her caregiver, Charlie, was generally considered to be the key to her support, and he was also said to need assistance. Almost all service personnel also said they thought that Mrs Osborne would have been eligible for help on a regular basis if she had approached them.

The sorts of assistance seen to be required varied somewhat between services. Home Nursing staff, for example, pointed to her need for nursing assistance, as incontinence was a major problem. Home Care staff, in contrast, reflected on her need for a home care assistant to help with household duties and to relieve the caregiver. Apart from these differences, the package of services suggested by staff from one of the Home Care Service agencies was typical of most others: regular deliveries of food could be arranged from a local shop and help with basic shopping provided; help with transport from the community transport service was required; an information visit and possibly ongoing help from a home nursing service (or possibly the incontinence prevention nurse from the Assessment Team)

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was necessary for her incontinence; help from Home Care could assist with housekeeping and with personal care (depending on her willingness to accept it); and regular visiting by a volunteer from the Community Aid and Information Centre could be arranged to overcome her social isolation. An updated comprehensive assessment from the Aged Care Assessment Team was also essential. In addition there was a case for assistance with some minor repairs and adaptations in the flat from the Home Maintenance and Modification service. Regular attendance at day care was also recommended to provide a social activity for Mrs Osborne and respite for Charlie. Several service managers spoke of the need for help with cooking, possibly using delivered meals from Meals on Wheels or a store of frozen meals.

To explain how it came about that people such as Mrs Osborne did not receive help from services, coordinators drew attention to factors associated with both the supply of services and the demands made by consumers. It was pointed out that like many people, Olive and Charlie may simply have wanted to remain independent and had therefore been reluctant to ask for help. Unless they formally requested assistance it would be difficult for services to find them. Several of the service managers and other personnel pointed out that in their experience, people often denied they needed help. Even if they were known, it would be unethical to impose assistance on them unless they requested it.

Another opinion offered by service managers was that Mrs Osborne had perhaps not known what help was available. The failure by key figures such as the general practitioner or hospital discharge teams to refer, or even to request a further assessment from the ACAT, was considered to have compounded the problem. GPs were considered essential as service mediators or referral agents, and there were many who worked closely with community services in Broadleigh. Nonetheless, failure to refer was said to remain an extremely common problem, indicative of the ignorant or hostile approach taken to community services by many doctors and other potential referral agents.

A third explanation advanced for the low level of service use concerned the prioritisation of applicants by service assessment staff. Even if Mrs Osborne had requested help from services, it was suggested, assistance may not have been offered if the caregiver gave the impression he was managing. This dilemma arose because there were simply not enough resources to go around. It was reported that it was sometimes necessary to give preference to people who lived on their own with no one to assist them. This explanation was, therefore, similar to the very direct and all embracing explanation offered by several other service managers - there are just not enough services available to meet needs, so no attempt was made to stimulate the use of assistance.

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Mrs Osborne's responses to questions about service use were revealing. The record of the final interview, for example, is as follows:

*Are there any other things you think you need help with that you are not getting at present?* No. (pause)... There's nothing I can't handle ...

*If you needed extra help, who would you ask?* I'd ask myself. ... or if I couldn't do it, I'd ask Charlie. *And if he was sick or couldn't do it?* If Charlie was sick, I would ring my daughter. (pause) I don't ask for much help. I think if I needed it, she'd help.

*Who would you turn to if they were not able to offer any help?* That wouldn't happen. ... I wouldn't ask services. No, that's not necessary. They've got enough to do.

*How do you feel about asking for help at home from community services, such as Home Care, Home Nursing or Meals on Wheels?* There's no reason why I should. I wouldn't use them because I wouldn't want to deprive someone else who needs services when I can look after myself at home.

Mrs Osborne's responses indicate a dogged spirit of independence, a close dependence on her caregiver Charlie and a wariness of rejection by service providers that had not been lessened by several unsuccessful attempts to arrange attendance at a day care centre. With little awareness of the sorts of facilities and services available and lacking any sense of entitlement to formal support, apart from that offered by her GP, she remained more or less cut off from the developments that had taken place with the introduction and expansion of the HACC program. Life at home, for her, seems to have been a self-evident symbol of independence. Recognition of a need for help from outsiders would have meant an admission of inadequacy and a betrayal of her trust in Charlie.

### Case Study Two

The second case study discussed with service personnel concerned Miss Fiona Price, a single woman aged 82 with Alzheimer's disease. Prior to the development of Alzheimer's disease, Miss Price had led a quite active life, but the rapid onset of the dementia led to a loss of social contacts. Her lack of insight and inability to either ask for or accept help resulted in an ever increasing dependence on her neighbours.

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Miss Price lived with her cat in her own ground floor flat. During the war she had been a nurse, and later, in her working life had been a shop assistant. When she retired she worked in voluntary work, first at Travellers Aid and later in Meals on Wheels. She had never married. Her only surviving family member, at the time of referral, was her 89 year old brother.

Her neighbours, John and Barry, who had both recently retired and were looking forward to some overseas travel together, rang the hospital asking for advice when it became clear to them that her memory had started to deteriorate. Ms Price's main problem was diagnosed at that time as probable Alzheimer's disease. The main symptoms noted were some memory loss and possibly some mild confusion. She could still shower, dress and cook for herself, but was unable to shop without assistance.

Although visited regularly by her GP, the only assistance Miss Price received was from her neighbours. At first, John and Barry organised her shopping and generally kept an eye on her. They were, however, worried about what would happen to her when they went to South America in a few months. Miss Price initially refused advice from the ACAT concerning possible assistance from services. Nevertheless, to help enable her to remain at home, some regular help was organised. Meals on Wheels delivered warm meals five times a week and a personal attendant from the Home Care Service of NSW came for two hours a day, five days a week, to help her shower, dress and clean the home, and to supervise her breakfast or lunch.

In the six months after her referral to the ACAT, Miss Price's condition deteriorated markedly. She became confused at night, woke her neighbours, left the gas stove on and became difficult to speak with. Although she had always been very fastidious, she refused to wash or change her clothes. She also became very demanding, inquiring constantly about her cat and about her recently deceased brother, from whom she kept expecting a visit. She also verbally abused her home help assistant, who then refused to attend. Thus, she became totally reliant on assistance provided by her neighbours.

John and Barry reported that there had been a period in which she had become very agitated, but she had since quietened down a little. Only a few weeks later, however, they complained about her aggressive and constantly confused behaviour, her waking them up at night, and so on. They were

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at wits end, and found the assistance provided by services to be of little assistance. The final straw came when the main assistance was withdrawn indefinitely by the Home Care Service coordinator who said she was unwilling to submit other staff to the same sort of reception already received.

Eight months after her initial referral to the ACAT, John and Barry, exasperated at the lack of assistance they were receiving, threatened the GP that if he did not take some responsibility they would call the police. Shortly afterwards Miss Price was admitted to a War Veterans Home, and after her case was heard by the Guardianship Board, transferred to a nursing home nearby to her flat. John and Barry continued to visit her regularly, and reported that she appeared to be much happier amongst the company of the new friends she had made.

The experience of Miss Price was selected as the second case for discussion because it highlights for us many of the problems associated with the care of dementia patients, particularly those living on their own. It also raises important questions about the capacity and orientation of community support services and the responsibilities of the GP in the referral process.

Among service managers there was a clear consensus that Miss Price and her neighbours had not received adequate help at home. They were reluctant to recommend a particular amount and mix of help, however, as they claimed a home visit and thorough assessment would be required to make an accurate judgement of her needs. Nonetheless, when pressed, most coordinators were prepared to nominate a number of different forms of assistance they felt were required. A typical recommendation was as follows: attendance at day care two times each week to relieve caregivers and help maintain Miss Price's interest, mental orientation and social contacts; regular visits by community nurses to organise medication, monitor Miss Price's condition and provide caregivers with advice; visits by a home care worker three times a day to supervise personal care, the serving of meals and medication and to help with housework; visits by the Dementia Visiting Service on the days Miss Price was not attending day care; the provision of prepared food daily by Meals on Wheels during the week and as frozen meals for home care to heat on the weekends, and regular assistance with shopping, perhaps from the community shopping service.

All coordinators believed that Miss Price needed much more help at home than she had been getting. Most, however, considered her admission to a nursing home as inevitable and perhaps even desirable. It was typically argued that it was not realistic to expect to prevent her admission for two reasons. First, because community services in Broadleigh were simply inadequate to provide sufficient

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care of the sort required to maintain her at home. Second, because it was inappropriate for her to remain at home in any case, as she was in need of constant care and was a danger to herself and others while she remained alone in her flat.

There were just two service providers who felt at all confident that services could enable Fiona Price to remain at home. The staff of the Community Options service argued that with extra funding, such as their service enjoyed, it was often possible to achieve significant results. They emphasised that the staff required needed to be specially trained in dealing with clients with dementia. The service coordinator who shared this view was responsible for the Dementia Visiting Service. She argued that her service, which provided daily visits of approximately two hours from trained staff, currently supported a great many clients like Miss Price who were able to continue living on their own. While not certain that such an approach would be successful, she claimed it was at least worth a trial. Both coordinators agreed that support provided by most of the existing HACC services would be unlikely to be adequate as it was discontinuous and therefore unsuitable. The staff of both services believed clients with complex needs and constantly changing health status, such as Miss Price, needed to be monitored and supervised regularly by a case manager.

Although service coordinators advanced a variety of different hypotheses to explain the problems Miss Price and her neighbours had in obtaining reliable help from services, they were as one in agreeing that the level and type of provision reported was unsatisfactory and that most of the problems experienced could have been avoided. They argued, however, that in practice problems such as those experienced by Miss Price were regarded as beyond the capacity of most services to respond to as part of their normal routine and were therefore 'put into the too hard basket'. When the system broke down, it was argued, such clients were often effectively abandoned. Although the correct practice is that such clients should be referred to other more appropriate services that are able to cater for their needs, this often did not occur.

One of the main problems identified by service managers concerned the relatively rapid development and variation of Miss Price's dementia symptoms. Services need to be able to respond to such complex situations, but generally relied on fairly static means such as irregular monitoring and advice from medical professionals, prepared meals five days a week and short visits from staff without specialised training in the area of dementia. As crises almost inevitably developed, this type of complex but standardised package of support was liable to prove to be too inflexible, and was difficult to adjust. Instead of intensifying and adapting their support, services were accused of often reacting by withdrawing, their response being to protect their own interests rather than to risk a possible open-ended commitment by taking responsibility.

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The client's apparent reluctance to accept help was seen as adding to the difficulties. Although suffering dementia, she repeatedly refused assistance, actively discouraged visits from service personnel and pointedly criticised the Home Care staff member assigned to help her. Despite the neighbours' pleas for assistance, respect for her rights to choose conflicted with any inclination to intervene. The absence of any mechanism for mediating this dilemma left services without a mandate to take responsibility. It was, therefore, not surprising that several service staff pointed out that the Guardianship Board (a legal tribunal with the power to assume or assign power of attorney) should have been called much earlier.

In the absence of a clear determination of the legal status of formal intervention, many service providers also questioned the actions of the general practitioner and felt that he should have played a more active part in obtaining support for Miss Price. Doctors are a common point of contact for most elderly people and the GP is a trusted guardian for many. It was argued that he or she usually sees the client on a regular basis and is in the best position to monitor them closely and advise of any readjustments to services to suit the situation. The lack of responsible initiative on behalf of the GP was made all the more acute by absence of a case manager from the Aged Care Assessment Team or elsewhere. It was widely acknowledged that clients can at times be 'lost in the system', especially when a worker leaves and hands her cases over to another person, as had in fact happened at the Assessment Team. This, they argued, highlights what they saw as a need for one person to take responsibility, as a key worker or case manager for such clients (Dant and Gearing, 1990).

Further, coordinators discussed the lack of resources which constrained their operation and prevented them from offering the sort and level of assistance they felt was needed. Often, all services could hope to do with the resources at their disposal, it was argued, was to supplement the work undertaken by a caregiver, offering such help as advice, respite, and some regular assistance in the home. Yet in this instance, Barry and John, the two neighbours ascribed the role of caregiver, had been reluctant to assume too much responsibility. As it would have been considered improper for them, as male neighbours, to become involved with intimate aspects of personal care, their reluctance was widely respected. In addition, almost all service managers emphasised the importance of recognising the limits of informal care. As caregivers, John's and Barry's rights to enjoy free time together also needed to be respected. Miss Price, nonetheless, needed ongoing supervision and companionship, every day and night. Services were simply not funded to provide this, it was argued, nor were they likely to be in the future.

Interestingly, there were three service managers who volunteered the thought that community services should not even try to provide full time support, as it would be

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both uneconomic and inequitable. The likely consequences of providing too much help would be that it would, over time, undermine the system of informal support on which most people who remained at home currently relied. The view was that community services were developed in addition to, and not in place of, nursing homes, and to perform their job well they had to recognise the limits.

### **Case Study Three**

The third case study discussed with service coordinators concerned a participant whom we gave the pseudonym of George Hatley. His situation, typical of many others in the study, serves to focus attention on the sorts of difficulties experienced by those who live alone despite significant levels of disability.

Mr Hatley was previously a window glazer, having worked his way through his trade to eventually become part owner of a glazing company in Victoria. When his wife died of cancer about fifteen years ago, his life, he said, 'fell to bits'. He now lives in a small, single person pensioner unit for the aged, part of a large Housing Commission development.

He was initially referred to the ACAT for assessment for admission to a hostel unit. Although this was approved there were no vacancies available at the time. He subsequently turned the offer down and has remained living in his pensioner unit.

At the time of referral, Mr Hatley's main health problems were related to his back and his weight. His spine caused him constant pain which forced him to sleep each night sitting in a chair. He also had become overweight and had problems walking. He could walk only short distances and relied on a walking rack and furniture to move around at home. He depended on his son Nigel for help with shopping and for meals on the weekend. During the week he ate and drank at a local sports club each day. At night he usually made a sandwich or opened a tin of spaghetti or baked beans for himself. Once a fortnight an assistant came from the Home Care Service for two hours to help clean the home.

A few months later Mr Hatley fell while trying to shower himself at home and was admitted to hospital for a week. On his return assistance from a home nursing service was organised, twice a week. The home nurse helped with

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showering and set out Mr Hatley's weekly medications in a dosette box. As a temporary measure, he was also supplied with frozen meals from the hospital for a few weeks. These had been cancelled as soon as he was able to attend the club again. He was also lent a walking frame by the hospital. A volunteer, whom Mr Hatley thought was probably from the local community centre, also came once to help take him to the optometrist.

Over the next year Mr Hatley lost some weight and had an operation for an artificial hip. In most other respects, however, his health and need for care remained relatively stable. On his discharge from hospital following the operation the help with cleaning he received from the Home Care service was reduced to half an hour a week. The help from the Home Nursing service, too, was reduced to just once a week to shower him and organise his medications.

In the winter of 1992 Mr Hatley fell over the radiator at home. His pyjamas caught fire and severely burnt his left leg. He was admitted to intensive care for two weeks and spent a total of 13 weeks in hospital. He required extensive skin grafts, most of which were taken from his right leg. He had just recently returned home at the time of the final interview.

The damage caused by his wounds and the skin grafts to his leg continued to cause him great pain and significantly affected his ability to remain independent. His wounds needed basic dressing (bandaging following the application of a cream) which, he said, he was able to attend to himself. Although he had lost a further 3-4 stone (20-25 kilograms) while in hospital, he had difficulty showering himself without assistance. He also became even more uncertain and unstable in moving around at home. He could still dress himself (after a fashion) without help, but was unable to undertake housework on his own. He continued to need help to shop and to leave the home. Nevertheless he wished to preserve his independence and wanted to remain at home. He claimed that, by and large, he could still look after himself and did not need much help. Each weekday he still arranged to catch a taxi to the club where he drank a couple of beers a day, talked with friends and ordered lunch which he generally brought home to eat.

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For the first three days after his discharge from hospital, Mr Hatley was visited daily by a home nurse, who attended to the dressing of his skin graft. After this, the home nursing visits were reduced again to once a week to attend to his dressings and to shower him, as he was unable to do that himself. Assistance from home care continued to be half an hour once a week. He was also visited at home by an occupational therapist who removed the radiator (but did not replace it with anything safer) and organised an additional support aid to make use of the toilet easier. He was anxious to replace his bed, which he was still not able to use, but the therapist seemed to have ignored this.

His main caregiver remained his son Nigel, who visited his father by train, usually twice each week, a little less frequently than previously. Mr Hatley's other son, Robert, lived nearby and also maintained regular contact. Some help was also received from various local people: one other resident popped in every day to see if Mr Hatley needed milk or bread, and another resident of the pensioner complex who delivered the newspaper each day. The chemist also had a delivery service which Mr Hatley relied on.

The prospects for Mr Hatley remaining at home were judged by most of the service providers to be good with the proper support, although dependent on his condition remaining stable. They felt that Mr Hatley was managing well and had a healthy attitude, was well motivated and active. Most service providers similarly thought that the assistance Mr Hatley received was adequate, although showering was too infrequent. As one coordinator put it 'Overall not too bad, but people do need a decent shower at least three times a week'. There was, however, some divergence in views about the sort of approach required and the appropriate mix and amount of assistance he required.

Service providers divided into two camps in the way they approached the case. The most common approach focused on his need for domestic support, which was seen to require an adequate, long term and stable set of support arrangements to maintain him at home. Emphasising his need for assistance with housekeeping, one of the field coordinators of the Home Care service suggested the following arrangements: home nursing staff to help him with showering, dressing his wound and monitoring his condition; once his condition stabilised, his ongoing care should be taken over by Home Care staff, who would clean his flat (2 hours a fortnight), and shower him five times a week (possibly, it was added, only 3 times a week, with a case review built in). His diet should also be examined to see if he could

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reduce his weight. Similar sorts of arrangements were suggested by many other HACC service personnel, some adding other possible services such as the Meals on Wheels service five days a week, help with shopping once a fortnight from the Community Shopping Service and contact with a Community Aid Service to help him deal with banking, administration and other irregular problems.

A somewhat different perspective, emphasising rehabilitation and activation rather than maintenance, was taken by the staff of the more health care oriented services. Staff from the three Home Nursing services and the Assessment Team, for example, spoke of the need for a complete medical check up to assess his level of fitness and mobility. An exercise and diet program to reduce his weight and increase mobility was also stressed as was the importance of an appropriate pain control regime, the introduction of more structured activities such as attendance at an alcohol free day care centre, visits from the mobile library and an assessment of the home by an occupational therapist to install handrails and remove hazards. Other forms of assistance such as help from a Home Nursing service to dress his wounds and Home Care to shower him were also recommended, similar to the domestic support approach discussed above. Another suggestion was that he may have required grievance counselling, as he may not have got over his wife's death.

To explain what they felt was a relatively low level of service use by Mr. Hatley, in comparison to what they felt he needed, service managers coordinators pointed to the need to respect the independence and privacy of clients. Because services aim to enhance the independence and respect the autonomy of clients, it was argued, it is often better not to allow them to become too dependent on help from outside. If Mr Hatley himself had wanted to remain independent, it would have been difficult in any case to justify imposing on him.

This sort of explanation was further justified by reference to both his personality or attitude, and the constraints on service resources. He may not have wanted help at home, or at least have given the impression that he did not want more help or that he could cope as it was, it was claimed. As one service provider pointed out, 'if someone is coping and they don't demand to be helped, it is easy to justify not providing assistance'. The sort of situation in which it is necessary to justify not providing assistance often arose, it was pointed out, where there are many demands on any service and there is a shortage of staff and other resources. Given the competition resulting from the high level of demand, Mr Hatley, it was explained, would probably be low on the priority list.

Mr Hatley's responses to questions give some credence to this explanation.

*Did they send anyone around to help you when you came out of hospital? They had the, um, sister around at the start. I think she only came round for a few days like. ... I think she*

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used to come around very near every bloody day. She was absolutely out of this bloody world. She's not a young lady. I think she was the head lady or something. I'll never forget her as long as I bloody well live. She was just something. People who love their job sort of thing.

*A really dedicated sort of person?* Yeah ... I'll never forget her. (Reaching out to show a piece of paper with a name and phone number.) That's her writing there. ...she was gospel, you know, if she'd have said jump over the fence I would jumped, even if I couldn't have jumped I would have fallen over or flown over or something.

*And it was she who decided that you could be helped just once a week instead?* Oh yeah, and you know she left a phone number there and if (there was) any trouble, you know, I could ring her. I've never forgot that lady.

So far he had not used the phone number. Later in the interview we returned to a similar subject.

*Is there any extra help you think you need?* I know I could get more than I'm getting now ... but I don't really want that. Some days its a hell of a lot better than other days. I think there's different types. If a person wants help he should be able to get it, but I'm not that sort at all, you know ...

*If you needed extra help, who would you ask?* No one here (the pensioner unit complex). I'd go without it, or do it myself. Maybe Hazel or one of the other neighbours would help. I ask one of my sons to get some shopping or something quite easy.

*How would you feel about asking for and receiving help from community services such as Home Care, Home Nursing or Meals on Wheels?* No, I'm not greatly interested in Meals on Wheels food. If necessary I could go back to Home Care for help with showering or whatever. I used to get help from them. ... But I wouldn't worry about asking them. If you ring them up you mightn't get help. They're not available like they used to be. I cut it out because they were too efficient. I'm too old to bother with that now.

Mr Hatley's reluctance to ask for extra help seemed to be part of keeping up the appearance of independence. He had always been a strong, proud man and was

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unlikely to want to humiliate himself by asking for further help. His admiration, indeed loyalty, for those who helped him, compounded the difficulty he had in asking for help, as he did not want to disappoint them by drawing attention to his vulnerability. But the explanation for his modest use of services can not be reduced simply to issues of personality, any more than it can be attributed to the cultural values of masculinity and the independence. Like the service managers, Mr Hatley recognised the limitations on the amount of assistance services could provide, and adapted to these as he was required.

### **Themes from the Case Studies**

The case studies were chosen because they represented contrasting patterns of need, service use, and outcome for the clients. Mrs Osborne, who lived with a co-resident caregiver, and Mr Hatley who lived alone, were both able to remain at home over the full three year period, despite making only limited use of community support services. Miss Price, in contrast, received services at a relatively high level of intensity for a limited time, but was unable to remain at home. But service use was not the only distinguishing factor. The nature and severity of the disabling condition, the extent of need for help that results from it and the availability of informal assistance all emerge as crucial factors for any explanation of the patterns of service use and the outcomes of support for the individual participant concerned. Given the contrasts between the case studies on these dimensions, the degree of overlap in the explanations provided by service personnel, participants and caregivers is particularly interesting.

One of the most marked features is the discrepancy between the patterns of service use recommended by service personnel and the actual pattern of service use recorded. In each case, participants reported receiving far less help from services than providers recommended. Importantly, service providers reported that this was not unexpected.

Virtually all service providers pointed to the inadequate funding of services, and hence inadequate supply, as the main cause of the low level of service use. But they did not attempt to reduce the issues to this single factor. Rather, there were a cluster of other factors tangled up with issues of inadequate supply which they sought to draw attention to. Some concerned issues of service provision, such as the lack of coordination between services, the inappropriateness of certain standardised forms of provision, the need for some form of case management or key worker in complex cases, and the need to prioritise clients in order of urgency. Others concerned the aspects of client behaviour, such as the reluctance of many older people to request assistance. Another set of factors related to what might be considered the philosophy and objectives of community care. These ranged from debates about the fundamental purpose of community services and whether they

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should be a substitute for nursing homes, through to the rationalisations of intervention as supporting independence and client choice. Similar themes were also encountered in the responses of participants.

One further important point to emerge from the case studies is the absence of any association between the intensity of service use and the viability of support at home over the longer-term. Despite the relatively low levels of service use evident in the cases of Mrs Osborne and Mr Hatley, both participants were able to remain at home throughout the entire study. From the evidence we presented, each was also considered by a series of experienced assessors to have good prospects of being able to continue to reside there.

In Mr Hatley's case, it seemed clear that the assistance received from Home Care and Home Nursing over a longer period, and the more intensive assistance received from the Home Nursing Service when he returned home from hospital had enabled him to successfully adapt to the circumstances in which he found himself and to avoid admission to a hostel. Possibly even more telling was the importance of the various aids, adaptations and appliances with which he had been provided. These had transformed his home into a form of accommodation that was well adapted to his needs, contributing to his capacity to remain at home perhaps more than any other single form of assistance. Although it seems clear that a higher level of service use would have been justified, the relatively minimal help he had received had been well targeted. Similar observations could also be made about the extremely low levels of assistance received by Mrs Osborne.

In contrast, the amount of assistance provided to Miss Price prior to the withdrawal of her home help was amongst the most intensive recorded for any participant in the study. Despite this relatively high level of support she was unable to remain at home. There were undisputed inadequacies in the package of assistance she received, most notably the absence of any support on the weekends. This, together with the collapse of her arrangements with the Home Care Service, also points to the unsuitability of the assistance made available, a point noted by several of the service managers and personnel who commented on her case. It is also doubtful that even the modest level of success achieved in enabling her to remain at home for more than eight months after her referral to the Assessment Team would have been possible without the contributions of her two neighbours.

Comparing the three case studies on this point is revealing because it serves to caution against the commonsense conclusion that increases in the amount of assistance provided by services enhance the viability and quality of life at home. The existing pattern of service provision and use may be ideally suited to certain types of need and patterns of support. They are clearly inadequate, however, for

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complex cases such as that of Miss Price in which there is an extensive need for ongoing skilled supervision that cannot be provided by informal caregivers.

## 8.5 Summary

The evidence presented in this section shows that participants made only a relatively moderate use of formal community support services. The contribution of formal services to maintaining people at home, however, is more difficult to document. This may reflect the relatively low levels of service use reported by participants and caregivers. Certainly there is some qualitative evidence from the study, some of which has been cited earlier in the report, to show that services such as home nursing, even when received in small amounts for only a short period, were crucial in helping individuals through a period of crisis. Nevertheless, given satisfactory housing and a social security system which ensures an adequate level of income for daily consumption needs, service provision remains the single most important form of public intervention for supporting those who require assistance to remain at home.

To explore issues of service use more fully we therefore turn our attention to the development, funding and operation of service provisions in Broadleigh in the next two sections of the report, before examining the processes associated with the allocation and use of services more closely in Section 11.

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## **9 The Development and Funding of Local Community Support Services**

In the previous sections of this report we discussed findings from the study concerning the experience of support at home over three years for the sample of participants referred to the Broadleigh ACAT who were the users or, more correctly, the potential users of community support services. In this and the following section we focus on the research concerning the provision of services to address the second research question underlying this study: What resources are provided to assist those who remain at home?

The section commences with a clarification of what is meant by the term community support services, and a brief account of the administration of the Home and Community Care (HACC) program in New South Wales and other Australian States. An overview of domiciliary service provisions in Broadleigh, based on a shortened and revised version of a survey presented in the first report from this study (Fine, 1992) follows. It is supplemented by an account of day care centres in Broadleigh, based on our survey conducted in 1992.

The account of service provisions presented in this section provides a background to the discussion in Section 10, in which we examine aspects of the performance of service work and discuss a number of issues associated with the organisation and operation of services.

### **9.1 Identifying Community Support Services**

At the broadest level, community support services may be thought of as formal organisations established to provide advice and practical assistance to people who, as a result of disability or chronic illness, require ongoing help to remain at home. Unlike hospitals, nursing homes and many other facilities and services which form part of the system for long-term care in Australia, community support services are not subject to any central registration system or licensing provisions (Grant and Lapsley, 1993). Under the *National Guidelines* of the Home and Community Care Program (1992b), the eligibility of services to receive funding is dependent on certain minimal conditions. Briefly, these state that the services receiving funding must meet the fundamental aims of the HACC Program, which are:

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- to provide a comprehensive and integrated range of basic support services for frail aged and other people with a disability, and their carers;
- help these people to be more independent at home and in the community, thereby preventing their inappropriate admission to long term residential care and enhancing their quality of life;
- and to provide a greater range of services and more flexible service provision to ensure that services respond to the needs of users. (HACC, 1992b: 2)

The organisations must also be legally incorporated, comply with any relevant State laws including licensing and registration laws, and operate in accordance with all ordinances (eg. health and building regulations) enforced by local government. In addition, they must adhere to equal employment opportunity policies and be eligible for accreditation where such standards apply (HACC, 1992b: 17-31; DSHS, 1994, private communication). These rather general conditions, which are concerned only with the eligibility of services for funding, stand in marked contrast to the much more systematic licensing provisions which govern the establishment and operation of other comparable services such as State registered health facilities, facilities eligible to operate under the Disability Support Program and child care services (DHHLGCS, 1993b). In particular cases, such as that of the Aged Care Assessment Team and community nursing services, stringent forms of State regulation are applicable. Rather than a characteristic held in common with other services, this is a legacy of their medical origin which serves to distinguish these services from other community support services.

The absence of a common system of licensing or registration meant that a preliminary task for the study was to identify relevant community support services operating in the Broadleigh area. A number of characteristics which distinguish them from other services were used to identify the community support services included in this study.

The first concerns their organisational characteristics. Services identified are organisations which have been legally constituted with a formal, codified and enduring system of governance, to operate and provide assistance without gain from profit. Spontaneous or informal acts of altruism, whether undertaken by an individual or group, and services provided for a profit which are not funded directly by the HACC Program, are thereby excluded from consideration. Other types of organisations which may also be important for assisting people remain at home, including privately operated home support services, acute health care services, (such as those provided by general practitioners, medical specialists and acute

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hospitals), and commercial services also available to the general public, such as home delivered groceries are thus excluded from consideration.

The second distinguishing characteristic concerns the service's purpose or goal of operation. Community support services are those organisations which exist to provide advice and practical help to people who, as a result of disability or chronic illness, require help to remain in their own homes. This distinguishes the organisations under consideration from other closely related service providers, including public hospitals, medical practitioners, and residential care facilities, which are not primarily intended to achieve these goals, as well as from other more generic types of community services, such as garbage collection and public transport, also used by those at home but not specifically intended to support those who need help as a result of disability or illness.

Drawing attention to the geographic locus of service provision, the third distinguishing characteristic is that assistance is provided on a local basis. Many of the more traditional welfare and charitable services, such as the Royal Blind Society, Legacy and the Australian Red Cross, which cover the entire State from a central headquarters, are thereby also excluded from consideration as community support services.

These three distinctive features together served as a means of identifying the relevant community support services operating in Broadleigh. They also serve to distinguish a range of organisations which have been established to operate in the public domain, usually with financial support from the Commonwealth and State Governments, which have as their specific mandate the provision of community support to those identified as being in need of assistance.

### **The Administration of the HACC Program**

In the HACC Program, decisions about the establishment and funding of community support services are taken at the State level. Funding for individual services is reviewed annually, with final approval required from both the State and Commonwealth ministers responsible for the program. The Commonwealth has agreed to match State increases in expenditure on a dollar for dollar basis, up to an agreed maximum. This was initially set by the Commonwealth at 20 per cent above the level of the previous year, then gradually reduced to 15 per cent, ten per cent and more recently, eight per cent in real terms (HACC Review, 1989; DHHCS, 1991a; Morris, 1994). Details of the service planning process followed in each State are set out in the annual State Strategic Plans.

The planning priorities spelt out in the New South Wales *State Strategic Plan for 1989/90* were as follows:

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- 1 To fill gaps in service provision and ensure that 'each service type is represented in each service area';
- 2 to ensure that resources are equitably distributed through sub-regional areas; and
- 3 to ensure that the level of service provision in each sub-region is adequate to meet the needs of each target group.  
(NSW DOCS, 1989: 12)

By 1990 the first two objectives were considered to have been largely achieved. The third objective, achieving adequate levels of service, had not been met. Although there is a consensus that more services are required, there remains considerable disagreement about what precisely an adequate level of service would be. Much faith was placed in the development of 'benchmarks of minimum service levels that will establish a total picture in regard to the need for HACC services' (NSW DOCS, 1989: 12), but so far these measures have remained elusive (Fine, Graham and Webb, 1991).

The administration of the HACC program in New South Wales is the responsibility of five separate government departments (the Departments of Community Services, Health, Housing, Transport, Local Government and Treasury) and a statutory body (the Home Care Service of New South Wales). The *1991-1994 Three Year State Strategic Plan* noted that consideration was to be given to bringing the program under a single administrative authority (NSW DOCS, 1991: 10), but these plans did not eventuate. Although nominally administered under the same program, the distinct character of many of the services encountered in each local area appears to owe much to differences in the funding approach taken by the separate State Government departments. Not surprisingly, the character of service provision in other states also owes much the respective administrative arrangements of the States concerned (Morris, 1994; Healy, 1994; Yeatman, 1990).

As in other States, a complicated consultative and advisory process was used in New South Wales as part of the planning process. This involved inputs from local agencies and consumers through the use of local regional and sub-regional HACC Forums as well as by direct submission. In addition there are a series of planning steps involving regionally based Community Project Officers, meetings of the Government Regional Officers Group (GROG), and the Joint Officers Group (JOG) involving senior officials from the State and Commonwealth departments, the advice of the State Advisory Committee and finally the agreement of the ministers from the State and Commonwealth Governments.

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## 9.2 The Development of Domiciliary Services

Community support services in Broadleigh, as elsewhere in Australia, developed under a series of administrative regimes in which each of the three levels of Australian government, Commonwealth, State and local government, assumed at least partial responsibility for the provision of community care services. An overview of services providing domiciliary assistance, including those responsible for providing information, referral or assessment, is presented in Table 9.1.<sup>30</sup>

The development of domiciliary services took place over a period of 35 years, following a pattern that can be loosely characterised as three 'generations' of services. Each generation of services appears to share particular operational characteristics closely associated with the conditions of its establishment.

### The First Generation of Services

Home Nursing and Meals on Wheels services, the first generation of community support services established in Broadleigh, began operating around the time that Commonwealth subsidies were first made available. This occurred following the *Home Nursing Subsidy Scheme* of 1957 and the *Delivered Meals Subsidy Act* of 1970 (McLeay, 1982). These national programs stimulated the provision of each service, directly shaping the way it was provided in each local area. The subsidy for delivered meals, for example, was payable only to voluntary organisations or local government bodies providing Meals on Wheels services. Under the Act, meals could be prepared at public hospitals, although they could not be delivered by them (Smith, 1984).

At the time they were established these services were closely associated with the Municipal Councils. Today they continue to provide assistance only within their respective municipal boundaries. In some instances the local initiative to establish a service was taken by service clubs, the Rotary Club of Municipality B being particularly active in this respect. In other cases the initiative came from the Municipal Council or from prominent aldermen on the Council. In all cases the Council has remained closely associated with their operation, although only one of these services, the Home Nursing Organisation of Municipality C became a full Council-owned service. Councils continue to provide some direct funding, access to rent-free premises and other forms of material assistance and administrative

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30 Some of the services submitted information regarding the year 1988-89, while others provided information on the basis of the financial year 1989-90 or the calendar years 1989 or 1990. In compiling the statistics presented in this section, budgetary figures have been adjusted to ensure consistency.

support. In addition councillors continue to sit on the Boards of Management of each of the services.

The specialisation of first generation services is reflected in their staffing. In the Home Nursing services, almost all personnel were nurses, although two of the three Home Nursing organisations also used volunteers for certain aspects of their operation. The Meals on Wheels services, in contrast, relied entirely on volunteers for delivering meals, with paid staff restricted to organising the production of meals and supporting and managing the volunteer labour force.

Community Aid and Information Centres initially arose as a response to national moves to stimulate locally based community organisation in the mid-1970s. Influenced by the philosophy of community development, which first came to the fore in Australia at the time of the Whitlam Labor government with the Australian Assistance Plan of 1974-76 (Hayden, 1978). Like the Meals on Wheels and Home Nursing services they were developed in close association with local government. The emphasis in these Centres has been providing information to the public about other services in the area. They have also been significant service innovators, promoting a range of innovative volunteer based activities and mutual aid programs in Broadleigh. Schemes developed more fully in the late 1980s under the HACC Program, such as Home Visiting and Community Shopping, have been sponsored and developed through some of the Community Aid and Information services. In this sense, although the organisations have some of the characteristics of first generation services, they represent a more transitional form of organisation which have much in common with organisations developed more recently.

### **The Second Generation of Services**

The second generation of services, the Community Health Centres, Home Care Services and the Broadleigh Aged Care Assessment Team, developed in the area during the decade from the mid-1970s to the mid-1980s. At the time they were established, each service was closely associated with the State Government. As local agencies for what are essentially state-wide services, these organisations have been able to command greater resources than other services. As organisations, they typically have the most complex staffing and administrative structures. The two health care based services, the Community Health Centres and the Broadleigh Assessment Team, are each staffed by a range of professional and para-professional personnel representing different fields of expertise. The Home Care Service also has a fairly elaborate division of labour in each branch, as well as a range of other specialised staff, such as interpreters, educators and advisers who are also available through the state wide organisation if necessary.

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Table 9.1: Overview of Domiciliary Support Services in Broadleigh: 1990(a)

Service Type Area Covered	Year Established	Range of Services	Auspice	Clients per week	Paid Staff			Volunteers	
					F/T	P/T	Hrs/wk	No.	Hrs/wk
Home Nursing Services									
Area A	1958	Nursing	Council Service	100	4	1	161	0	0
Area B	1960	Nursing	Council Sponsors	65	6	2	243	6	15
Area C	1966	Nursing and Day Care	Council Sponsors	230	17	2	686	13	52(b)
Meals on Wheels									
Area A	1967	Food	Council Sponsors	155	0	2	22	105	225
Area B	1964	Food	Council Sponsors	130	0	1	20	50	125
Area C	1967	Food	Council Sponsors	215	2	7	172	110	275
Community Aid and Information									
Area A	1975	Information	Com. Mgt.	95	0	9	169	63	186(c)
Area C	1975	Information	Com. Mgt.	10	1	1	38	43	-
Community Health Centres									
General Health Care Team(d)									
Areas A, B, C.	1975-82	Nursing + paramedical	Area Health Board	310	17	3	671	0	0
Home Care Services									
Area A, B.	1985	Personal care, housekeeping, etc.	Home Care Service of NSW	650	8	82	1,376	0	0
Area C	1980			550	6	57	1,122	0	0
Aged Care Assessment Team									
Area A, B, C.	1983	Assessment, paramedical, day care	Area Health Board	320	25	14	1,132	8	30(e)

Service Type Area Covered	Year Established	Range of Services	Auspice	Clients per week	Paid Staff			Volunteers	
					F/T	P/T	Hrs/wk	No.	Hrs/wk
<b>Community Transport</b> Area A, B, C.	1983	Transport	Com. Mgt.	200	3	1	135	62	426
<b>Community Shopping</b> Area A, B, C.	1987	Shopping	Com. Mgt	86(f)	0	3	43	64	32
<b>Home Maintenance and Modification</b> Area A, B, C.	1987	Building repairs etc.	Com. Mgt.	12(g)	2	1	100	0	0
<b>Dementia Monitoring Service</b> Area A, B, C.	1988	Dementia monitoring	Com. Mgt.	20	0	18	96	0	0
<b>Volunteer Training</b> Area A, B, C.	1987	Training	Com. Mgt	-	2	0	72	0	0
<b>Community Options</b> Area A, B, C.	1988	Case management and Brokerage	Home Care Service of NSW	90	3	0	105	0	0

- Notes: a) All funding and client service figures presented in this table have been rounded to facilitate tabulation and preserve the confidentiality of the individual services. Abbreviations: 'Com. Mgt.', Community Management; Ft, full-time staff; Pt, part-time staff; Hrs/wk, total hours per week.
- b) Volunteers assist with day care activities only.
- c) Figures include volunteers for other services, such as child care, recreation, etc.
- d) Figures based on General Health Team only.
- e) The figures refer to voluntary staff of day care centres included in service data.
- f) Total number of clients per week, assisted on a fortnightly basis.
- g) Numbers vary considerably from week to week. Figure is weekly average, based on annual total.

Second generation services were established in a way which enabled them to tackle a far broader range of tasks than first generation services. A core service activity could be identified for each service. For the Home Care branches this was housekeeping, for the Community Health Centres it was home nursing, and for the Aged Care Assessment Team it was the conduct of multidisciplinary assessments and the provision of advice. But in addition, each organisation also provided a more diversified range of assistance. Some of the additional services offered by the Home Care Service, for example, included personal care and in-home respite services, gardening and 'noxious cleaning' of unwanted household possessions and accumulated waste. In addition to home nursing, the Community Health Centres provided social work, counselling, general health advice, health promotion services and, in one Centre, physiotherapy services. The Aged Care Assessment Team also diversified from a small team concerned solely with advice and assessment to become a relatively large service providing day care, dementia monitoring and continence promotion services, as well as other forms of advice and assistance. The Team also operated as the centre for the distribution of disability aids and appliances.

### **The Third Generation of Services**

The third generation of community support services was established in the mid-to late 1980s. All of these services, except Community Transport, owed their development to the HACC program, first introduced in New South Wales in 1986, and each was responsible for service delivery to the entire Broadleigh locality. With the exception of the Community Options service (discussed below), the organisations were established as a result of initiatives taken by previously existing Community Aid and Information Services, and in a number of instances continue to operate from the founding organisation's premises and operate as if they are a part of that organisation. All have remained directly accountable to what was described to us as 'community based' Boards of Management, that is a voluntary governing body consisting of representatives drawn from the local community, elected annually at a general meeting open to the public. With the exception of Community Options, all third generation organisations provide highly specific forms of assistance. Although more organisationally complex than the single task services of the first generation, each service continues to operate under the umbrella of the founding organisation. Most third generation services could be justifiably characterised as semi-autonomous work units within a larger community service setting, rather than as autonomous and specialised services. Nevertheless, for reasons associated with the conditions of funding, these services were established as legally discrete entities.

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### Sources of Funding for Domiciliary Services

Differences in the operation of individual services and service types associated with their development were also underpinned by differences in the sources and types of funding received by each organisation. In this regard one of the most revealing findings of the survey of domiciliary services is that most services were not funded solely by the HACC Program. Data collected in 1990, (see Table 9.2) show that a wide variety of sources were involved in funding domiciliary services, as was the case for day care discussed later in this section. Although more than half of the total funds for the local system were derived from the HACC program, crucial shares also came from other sources.

The proportion of total funds contributed by the HACC program was reported to be lowest amongst the first generation of services, that is those which had been established the longest and were most closely associated with local government. No more than a third of total funds were contributed by the HACC program to any of these services. They relied, instead, on assistance provided by local councils (both directly and indirectly), on client fees and on contributions from other sources including interest from savings, occasional bequests from former clients and monies raised by various fund-raising activities. Other domiciliary service organisations which also reported a relatively low proportion of funds from the HACC program include Community Health Centres, the Aged Care Assessment Team, the Community Transport Service and the Home Maintenance and Modification Service. The first two of these organisations received most of their funds from the New South Wales Department of Health. The Community Transport Service and the Home Maintenance and Modification Service supplemented HACC funding with income from other State Government programs and with fees charged to clients. The proportion of funding received from the HACC program was considerably greater amongst the remaining services, constituting between 75 and 95 per cent of total funds.

The diversity of funding sources is an important indicator of the relative autonomy of individual services. Organisations receiving funding primarily from one source were constrained in many ways by the conditions attached to that funding. Where funding came from a number of different sources, organisations gained a degree of independence as no single funding agency was in a position to control or direct their operation. Recognition of the diversity of funding is also a key to understanding the limited capacity of any single authority such as the HACC program coordinators or the State Department of Health to manage the operation of the range of services available.

Related to the services' capacity to operate independently is the issue of the collection of client fees. Many service agencies, including the Community Aid and

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Table 9.2: Sources of Funds for Domiciliary Service Organisations in Broadleigh: 1989-90.

	NSW Dept of Health	Percentage of Estimated Total Funds, 1989-90.				Est. Total All Sources	Expenditure (\$'000)
		HACC Program	Client Fees	Council Funds	Other Sources		
<b>Home Nursing Services</b>							
Area A	0	34	10	43	13	100	190
Area B	0	34	17	34	14	100	227
Area C	0	28	16	44	13	100	670
<b>Meals on Wheels Services</b>							
Area A	0	24	70	3	4	100	122
Area B	0	31	49	13	7	100	60
Area C	0	21	44	30	5	100	230
<b>Community Aid and Information</b>							
Area A	0	0	0	11	89	100	40
Area C	0	0	0	23	77	100	35
<b>Community Health Centres</b>							
General Health Care Team	92	8	0	0	0	100	710
<b>Home Care Services<sup>(a)</sup></b>							
Area A, B.	0	88	11	0	0	100	950
Area C	0	88	11	0	1	100	580
<b>Broadleigh ACAT</b>	56	25	0	0	19	100	1,300
<b>Community Transport</b>	0	63	15	0	22	100	145
<b>Community Shopping</b>	0	93	0 <sup>(b)</sup>	0	7	100	45
<b>Home Maintenance and Modification Service</b>	0	74	20	0	7	100	140
<b>Dementia Monitoring Service</b>	0	100	0	0	0	100	45
<b>Volunteer Training</b>	0	99	0	0	1	100	60
<b>Community Options</b>	0	100	0	0	0	100	190

Notes: a) Figures provided by branch managers adjusted according to sources outlined in State Annual Report.

b) A transport fee of \$3 per fortnight is charged to each client. These fees do not appear in the service's budget, although they may be recorded as part of the budget of Community Transport.

Information Services, the Community Health Centres, the Aged Care Assessment Team and the Community Options Service, provided help to clients without cost. Clients of other services, however, were expected to pay for the assistance they received. Generally this was in the form of a service fee, with a standard amount being levied for each individual visit or unit of service. However, there was a notable lack of uniformity in the amount charged and the method by which a total weekly fee was calculated. The lack of a uniform approach amongst services in Broadleigh appears to be typical of services elsewhere in Australia (DHHCS, 1991a; Morris, 1994).

For example in 1990, two of the Meals on Wheels services charged clients \$10 a week, while in the neighbouring municipality clients paid only \$5.25 a week for what many considered to be a better quality meal. The cost of assistance therefore depended not on the needs or financial security of clients, but on where they lived. In another example, one of the Municipal Home Nursing services charged a standard fee of \$4 per visit. Their clients paid a weekly amount which was proportional to the number of times they were visited. Someone receiving nursing assistance twice a week would pay \$8, while another visited twice a day, five days a week, would be charged \$40. The Home Nursing Service in another municipality levied charges using a fee-for-service schedule. According to the schedule handed to clients in 1990, the lowest of these charges was \$2.50 for bathing, showering or sponging a pensioner. Enemas cost a pensioner \$12.50 for the first hour and \$3.00 per quarter hour thereafter. Private patients or patients in receipt of the Domiciliary Nursing Care Benefit were charged \$25.00 for the first hour for an enema, and thereafter \$6.00 per quarter hour. In the third municipality, clients of the Home Nursing service were charged a flat cost of \$5.00 per week, regardless of the amount or type of assistance they received. Nursing assistance provided by the Community Health Centre service was, in contrast, free of charge.

Not only were there differences in the charges levied between types of services, there were also different charges imposed for the same form of assistance provided in different areas as well as for those provided by different organisations operating in the same areas. In some cases a conscious attempt was made in the referral process to ensure that clients have access to services which they can afford, but this choice was not always available. Some low income clients who could not afford to pay the charges levied by Council based Home Nursing Services, for example, were referred on to the Community Health Centres where assistance is provided without charge. Such a referral strategy was not, however, possible for those who require Meals on Wheels, as each service operates within one municipal area only.

An alternative approach to the levying of fees which emphasised the clients' choice of fee was employed by the Home Care Service until 1991. Instead of using a standardised schedule of charges, Home Care managers reported that clients were

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asked to suggest how much they felt they could afford to pay for a particular service when they were first visited for assessment, although the actual cost of providing assistance was estimated to exceed \$25 an hour. The amount suggested by clients, it was reported, was accepted. Charges therefore varied according to a range of subjective and objective factors, including the actual financial circumstances of clients, their perceived financial well being, their generosity and level of gratitude.<sup>31</sup> This system was modified by the introduction of fee guidelines by the Home Care Service of New South Wales in 1991-92, which was intended to ensure low income clients received services at relatively low or even no cost, while those on higher incomes paid proportionally more, according to an income based fee scale, or sought assistance from private providers.

Fees for the Home Care Services were introduced as part of a statewide policy change explicitly intended to act as a rationing mechanism. In most other instances fees were decided independently by local services. They were justified in several cases by service managers as a revenue raising or cost recovery measure. By providing services with an independent income flow, the collection of fees also had the effect of ensuring that a proportion of each service's funds was not tied to the funding conditions of a government grant. For some clients, variations in the cost of using services may have proved sufficient incentive to encourage shopping around between alternative providers. In addition, it is likely that the levying of fees, whatever its rationale, may also have served to reduce the demand for assistance.

### 9.3 Day Care Services in Broadleigh

The development of day care services in Broadleigh differs in a number of interesting and important ways from that of the domiciliary services alongside of which they grew up. The first day care centres were established in Broadleigh in the late 1970s and 1980s initially as a service for nursing home residents (NSW Health Commission, 1981). Many such day care centres for nursing home residents still exist in Broadleigh today,<sup>32</sup> although the most significant development of day care services in recent years has been for people who continue to live at home.

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31 Users receiving Home Care in our study reported paying a range of fees, from \$2.50 to \$6.00 an hour. There did not appear to be any link between weekly income and fees paid.

32 A number of such centres continue to operate in Broadleigh, although, as noted below, they have been excluded from this study.

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### Identifying Day Care

Following the definitions of other writers on day care, (Howe, 1983; Nies, Tester and Nuijens, 1991; Brocklehurst and Tucker, 1980; Carter, 1981a), only centres which catered for frail elderly and other people living at home in need of support as a result of disability were included in the study. To be included, services also had to be open for at least four hours at least one day per week, and provide transport for those attending.

A total of 15 day centres for community support clients in Broadleigh were identified using these operational criteria.<sup>33</sup> Fourteen other social groups and day centres to which we were referred by community information pamphlets and other sources were screened out, usually because they were centres for nursing home residents, or did not meet at least once a week, or because they were primarily recreational social groups for the healthy. Senior citizens centres, and clubs for pensioners and retirees were also excluded. Many centres in Broadleigh went out of their way to ensure that they were not publicly identified as providers of day care, as it was argued the term 'day care' served mainly to discourage potential participants. Amongst the titles used were Frail Aged Group; Friendship Club; Friendship Centre; Friendship Group; The Friendly Club; Frail Aged and Disabled Group; the Frail Aged Disabled Group; and Day Group. The array of names was replicated amongst centres which catered for people from a non-English speaking background. The term day care was used in Broadleigh in only two cases.

### The Funding and Development of Day Care Centres

Like the domiciliary services discussed earlier in the section, the operation of day care centres in Broadleigh was closely related to their funding. It is possible to distinguish two broad categories of day care service in Broadleigh, on the basis of their source of funding. Variations in other organisational characteristics such as the centre's affiliation, frequency of service and staffing are closely related to the source of funding, as shown out in Table 9.3.

Services in the first category (A), which we have labelled 'HACC-funded centres', receive most of their funding from the HACC program or other government sources. Although the amount and actual source of funding reported differs significantly between centres, these services tend to have at least some professional or qualified staff and to have been established as affiliates of existing health or community services. Amongst this group it is possible to identify five major

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33 In the case of three centres included in the study, the criterion of a minimum of four hours of operation included time spent transporting participants to the centre.

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**Table 9.3: Organisation of Day Centres in Broadleigh: Frequency, Size, Auspice and Funding.**

Day Centre Pseudonym	Days /week open	Available Places/day(a)	Current Auspice	Main Source of Funding	Year Founded
<b>A: HACC Funded Centres</b>					
Banksia Cottage	5	12	ACAT	HACC	1987
Ti Tree Frail Aged	5	21(b)	Council Nursing Service	HACC	1989
Waratah Caring Centre	4	20	Church Based	HACC	1978
Flame Tree Day Care	3	20	Church Hospital	Hospital	1982
Multicultural Centre	3	16	Migrant Centre	HACC	1991
Angophora Friendly Clubs	2	30	Community Centre	HACC	1980
Boronia Seniors Group	1	16	Community Centre	HACC	1989
Gumtree Group(c)	1	8	ACAT	HACC	1991
Grevillia Gardens	1	9	Retirement Village	HACC(d)	1991
<b>B: Independent Community Groups</b>					
Eucalyptus Frail Aged	1	15	Community Group(e)	Self-support	1979
Wattle Frail Aged	1	15	Community Group(e)	Self-support	1980
Silky Oak Friendship Group	1	12	Church Group	Self-support	1982
Acacia Friendship Centre	1	42	Church Group	Self-support	1979
Callicoma Club	1	90	Community Group	Self-support	1983
Broadleigh Stroke Group	1	50	Self-Help Group	Self-support	1986

Notes: a) Attendance numbers are estimates only.

b) On one day per week, used for hydrotherapy, attendance is restricted to 10 people.

c) Full title: Gumtree Group for Brain Impaired Adults

d) The day centre opened in the last two years and was initially funded by the non-profit retirement village which established it. It was recently granted HACC funding and now operates two days per week.

e) These groups were loosely associated with Area Health Board Services

services, which operated three or more days a week and between them provided approximately 310 day places per week (i.e. the number of places per day by the number of days open each week), and others, which were open only one or two days each week and provided a total of just over 100 day places.

The second category of services (B), which we have labelled 'independent community services', was made up of day centres not formally affiliated with any

other community service agency. Together, these centres provided a total of approximately 225 day places per week. These centres had been established independent of government initiatives by church committees, self-help groups or, in one case, by a committee affiliated with a service club operated by the Returned Servicemen's League (RSL). Centres in this second group did not report any direct assistance from the HACC program or other government sources. Instead, these services tended to rely on the contributions of participants, volunteers and their founding bodies.

Obtaining accurate details of the budgets of each of the day centres in the study proved difficult, and the information available to us on the matter of finance remains incomplete. That which is available indicates that differences in funding underlie many of the differences in the operation of day centres in Broadleigh.

All day care centres in Broadleigh which provided information reported that they charged a daily attendance fee to all participants. This fee, which varied from one to five dollars a day, usually covered part of the transport costs (this was mostly said to be the petrol) and the costs of the food and drinks provided at the centre. Beyond this common element, however, there were considerable differences between centres in the official subsidies received. The greatest contrast in this regard was between HACC funded centres and those operated by independent community groups. Differences in this regard explain both the greater number of paid staff available to some services and the differences in the frequency of their operation. Services without funding were reliant largely on the contributions charged participants, on the voluntary services of unpaid staff, and on the donation of other resources, in particular of the halls and transport. These constraints, which prevented the centres from opening more than one day per week, also appear to have affected the program of activities provided.

Significant differences were, however, also evident amongst HACC funded services. In one instance, a day centre open four days a week received sufficient HACC funding to pay for only around 60 per cent of the wages of the coordinator. All other expenses -accommodation, transport, food, other staff costs and so on- were funded either by the contributions of participants or the fund raising activities of the church based auspice group. In contrast, at least two other day services in Broadleigh received much greater amounts, up to ten times this amount of funding through the HACC program, sufficient to employ several qualified staff members, pay for transport, and some of the costs of accommodation, and provide a varied and more complex program of activities. One of the differences in the funding which may explain the extent of variation was that centres receiving the larger amounts were operated by existing community health agencies and were funded by the HACC program through the New South Wales Department of Health. The service receiving the lower amount, in contrast, was a church based group not

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affiliated with any existing health service that was funded through the New South Wales Department of Community Services.

### **The Aims and Characteristics of Day Care Centres**

Differences in the funding of day centres thus appear to explain much of the way in which day centres in Broadleigh operate, as can be seen in Table 9.4. In most centres, the aim of day care was described as providing both an opportunity for participants to leave their homes and enjoy social interaction with others; and a means of enabling their caregivers to enjoy a brief but regular period of respite from their responsibilities. The way in which these aims were implemented, however, varied considerably between centres. The following case notes describe an observation visit to a day care centre established by the Broadleigh Aged Care Assessment Team.

**Banksia Cottage** operates five days a week to cater for people with moderate to severe dementia. It was established specifically to assist those with severe behavioural problems or physical conditions such as incontinence who were difficult to accommodate in other centres. A maximum of twelve people can attend on any particular day. The centre is located in a converted suburban house, and is not easily recognisable as there is no official sign to indicate its use. Inside, there is only a small common area for group activities. This consists of an open kitchen/lounge area with two dining tables and chairs in one corner, and a piano and a lounge suite and some easy chairs around the walls. The furniture can be easily moved to create an open space for games and exercises. A smaller sunroom attached to the kitchen can also be used. On the day of our first visit it was being used by a group of men for their morning tea.

There were four staff members employed to work at the centre on any one day: an occupational therapist, two recreational officers, and the bus driver/general help. They said they aimed to create a happy, safe environment with activities that were familiar and which provided mental and physical stimulation to those who attended. Participants were brought to the centre by 10.00 am. by the day centre bus. They were welcomed with morning tea in the kitchen. After this they were moved into the lounge area where games such as quoits, balloon tennis, and lounge room football were organised for all participants.

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Table 9.4: Operation of Day Centres in Broadleigh by Selected Characteristics

Day Centre Pseudonym	Own Bus	Own Venue	Hours per day(a)	Percentage Unpaid Staff	Medical or Para- medical Help	Client Groups(d)
<b>A: HACC Funded Centres</b>						
Banksia Cottage	Y	Y	6	0	Y	A B C
Ti Tree Frail Aged	Y	Y	8	25	Y	A + Gen
Waratah Caring Centre	-	Y	6	80	-(b)	A + Gen
Flame Tree Day Care	Y	Y	8	50	Y	A + B
Multicultural Centre	-	-	7	0	-	C + Gen
Angophora Friendly Clubs	Y	-	6	55	-	Gen
Boronia Seniors Group	-	-	4	25	-	Gen
Gumtree Group	Y	-	8	25	-	A + B
Grevillia Gardens	Y	-	8	65	-	Gen
All A(c)	66%(c)	44%(c)	av 6.7(c)	av 36(c)	56%(c)	
<b>B: Independent Community Groups</b>						
Eucalyptus Frail Aged	-	-	4	100	-	Gen
Wattle Frail Aged	-	-	6	100	-	Gen
Silky Oak Friendship Group	-	-	4	100	-	Gen
Acacia Friendship Centre	Y	-	6	100	-	Gen
Callicoma Club	-	-	6	100	-	Gen
Broadleigh Stroke Group	-	-	7	92	Y	B + Gen
All B (c)	17%(c)	0%(c)	av 5.5(c)	av 99(c)	17%(c)	

- Notes
- a) Operating time includes travelling time.
  - b) Assistance provided with toileting if necessary.
  - c) Percentages and averages calculated on the basis of total client numbers per week.
  - d) A: Priority given to clients with severe disabilities.  
 B: Priority given to clients with particular type of disability, disease or condition.  
 C: Priority given to clients from non-English speaking backgrounds.  
 Gen: 'General' community support clients, eligibility criteria does not specify level or type of disability.

This was said to provide mental stimulation and gentle exercise as well as an opportunity for participants to undertake activities with others. In the background 'golden oldie' tunes were played and at different times the participants would spontaneously sing along.

After lunch, some participants were taken for a walk. Others could have their feet or hands attended to, or have their hair done by staff. Four afternoons a week an additional personal care attendant was also present as many participants often become agitated towards the end of the day. Some of the participants who had experience as office workers would sit in the office for long periods. Others needed constant attention. One man, for example, was agitated the whole time. He was constantly on the move, wandering around asking for water and sweets, for which staff had a special supply.

Participants were brought home at about 3.00 pm. As in the morning, some of them sat in the bus for an hour or more, their trip being perhaps the most time consuming activity of the day. The bus was driven by a paid driver who knew each of the passengers and often provided an important link between the centre and their family. The other three members of staff remained at Banksia Cottage to complete a record of observations on each participant.

Banksia Cottage was unique in a number of ways. It was perhaps the smallest of the well established services, with a maximum of 12 participants attending on any one day. It was also the only day centre open five days a week.<sup>34</sup> Four of these days were organised and sponsored directly by the Aged Care Assessment Team using funds provided by the HACC program. On the fifth day, funded by another HACC funded service in Broadleigh, it provided what was called 'ethnic day care', catering exclusively for moderate to severely confused and demented clientele from two non-English speaking cultures. Banksia Cottage was also one of only two centres deliberately established to serve a particular medically defined clientele and, most importantly, it was perhaps the best staffed and resourced centre that we encountered.

Nevertheless, many aspects of its operation typified that of almost all of the other centres in Broadleigh. Activities generally had the character of informal social recreation and were usually carefully planned according to a fairly structured

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<sup>34</sup> It has since commenced operation six days a week.

schedule. The needs and capabilities of participants, the number of staff available and the physical attributes of the venue had all been considered in planning this schedule. Although few centres enjoyed such a high client staff ratio or were able to draw on the proportion of qualified staff available to Banksia Cottage, other day centres operated with a coordinator, often, although not always, a paid registered nurse or social worker, who was assisted by others, either paid staff and/or volunteers.

Banksia Cottage was also the only centre which operated from a suburban house. Although the venues in which the centres operated generally accommodated a larger number of participants, attendance and activities were restricted by the limitations of staff. Thus, while most centres had from between 15 to 30 people each day, they did not usually accept participants who were severely disturbed. To manage the larger number of participants under these conditions, activities were generally group oriented. Bingo, quizzes, craft and group sing-alongs were particularly popular forms of activity in most day centres. All centres also served morning tea and lunch to participants. Often entertainment of various kinds was provided on a regular basis. This could be the appearance of a variety act, a church or school choir, a film or slide show, which usually took place immediately after lunch. Most centres also organised occasional outings for participants.

Wattle Frail Aged Day Centre is an example of a centre which operated without many of the advantages of funding and staff enjoyed by Banksia Cottage.

**Wattle Frail Aged Day Centre** operates one day a week from a fairly new church hall set back somewhat from the main road. Although the centre was originally established with help from health care workers from the Area Health Service, it is now run entirely by a few volunteers, all of whom, with the exception of the bus driver, are women aged in their 50s or 60s. On any one week at least two of them are in attendance. The centre caters for around 20 people, although on any particular week the actual numbers are likely to be a few less than this. Most of those attending are confined to their homes for most of the week. They were all, however, able to use the toilet without assistance, as they could not otherwise be accepted at the centre. The coordinator said she could accept people who were hard of hearing as well as those who had memory problems, as long as these people were not disruptive. There had been occasions when she had to arrange for participants to be withdrawn from the centre because they could not be properly accommodated, given the centre's complete reliance on untrained volunteer staff.

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Participants arrived at the centre each Tuesday morning at about 10.30 a.m., having been collected from their homes in the surrounding suburbs by the Community Health Service's bus lent out each week to the Wattle Centre. Most of those attending were able to negotiate the few steps down from the car park to the hall. For those in wheelchairs or reliant on walking frames, it was possible to use another, longer route. Inside, the hall was light and warm, with seats arranged around two large round tables. There were flowers on each table and a handwritten placename for each participant. All in all the centre had a homely, unprofessional and unpretentious atmosphere, which participants and volunteers alike seemed to appreciate.

When they arrived, participants were each served with a bowl of soup and bread and butter. Because it was the bus driver's birthday the volunteers had also baked a birthday cake which was served at that time, accompanied by the necessary songs and cheers. After this the day's program began in earnest. Each week the volunteers go to some effort to put together a different program of activities. This week it was father's day, so there was a father's day quiz, and father's jokes to follow the light exercises set to music from a cassette player. After this participants also played quoits, answered more quiz questions and listened to songs. Then a lunch of sandwiches, fruit, yogurt and tea or coffee was served.

In the afternoon a game of bingo was organised. For those people who were hard of hearing or who did not like bingo, there was a game of carpet bowls. Some of the participants went outside during these activities, where there were chairs arranged so they could sit in the sun. The afternoon activities were soon over, however as the bus had to leave by 2.30 p.m. Before leaving all the fathers attending the centre were given a small present by the volunteers, which they had made themselves.

In Wattle Day Centre, as in almost all other centres in Broadleigh, social activities dominated the program of activities. With the exception of Banksia Cottage and one other centre, day care centres in Broadleigh were not established as venues for active therapeutic or clinical intervention. There was some recognition of the potential contribution of day care to maintaining people in need of care in their own homes, but this was generally restricted to seeing day care as a form of respite for caregivers and a means of overcoming the social isolation of the housebound. Other possible uses of day care facilities, which would have enabled the ongoing

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monitoring of individual clients, or provided medical, paramedical or nursing assistance to those attending, were not emphasised.

### **Day Care Facilities**

Four of the five major day care services used specially dedicated premises. In contrast, all other services relied on borrowed or improvised premises. Several of the HACC funded services operated in such venues as Senior Citizens Centres, premises provided by existing Community Health Centres and Community Centres. Because these arrangements necessitated sharing space with other groups, there was often a somewhat temporary, makeshift atmosphere about them. This improvised character was even more apparent in centres operated by independent community groups, which were all held in church halls.

A similar situation was encountered with regard to transport. Three of the five HACC funded services owned and operated their own bus. In most other instances, however, day centres relied on buses driven by Community Transport volunteers. In a few cases this was reported to be supplemented regularly by the loan of a vehicle by church groups or Community Health Centres. The availability of transport was said by coordinators to be one of the most important factors constraining the frequency of service and limiting the number and type of people who can attend.

The operating times of day centres, the number of participants attending per day, and the type of activities provided also reflected the source of funding. Unlike child day care, which nowadays tends to operate from early morning till evening in Australia (eg. 7 a.m. to 6 p.m.) all day centres in this study reported limited hours of operation. HACC funded centres, however, were open, on average, for more than an hour longer than independent community centres. In both types of centre, clients typically attended day care only four or five hours each day, from 10.00 or 10.30 a.m. until 2.00 or 3.00 p.m., their hours away from home being extended somewhat by the time spent travelling to and from the centre. For someone picked up first and dropped off last, this could involve as much as an extra three hours per day.

The fifteen day centres identified reported that they provide a total of over 635 day places per week, between them. Most were relatively small ventures in which daily attendance was restricted to a maximum of 15 to 30 people. Their small size was generally regarded by coordinators as a desirable attribute, necessary to create a homely and friendly atmosphere for participants and staff. This, however, was only part of the story, as the number of participants was also restricted by the space available, limitations on resources such as transport and staff and by the need to keep the task of supervision manageable.

The three services with the largest daily attendance, were managed by independent community groups. Two of these centres regularly had around 50 people attending, while the third reported that they have between 85 and 95 people each week. In

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these centres, each open only one day each week, however, a more liberal approach to attendance was taken than in other centres, where a relatively strict control was maintained over the numbers attending.

Differences were also apparent in the activities undertaken. Almost all centres provided a program of social and recreational activities, with most centres providing morning tea and lunch for participants. None of the independent community services and only three of the HACC funded centres provided medical, nursing or paramedical care. Those few which were able to assist participants who need help using the toilet were all receiving HACC funding. Nevertheless, despite some differences between centres, almost all provided a program of general, non-therapeutic activities intended to give caregivers at home a temporary break and provide participants with an opportunity for regular interaction with others outside their household.

The staffing arrangements and types of clients served similarly reflected the centre's funding and organisational background. With only two exceptions, all centres reported that they relied on volunteers for the daily operation of the centre, as well as for transport. In the day centres operated by independent community groups, volunteers constitute almost the entire workforce, contributing over 99 per cent of all hours worked. The only paid staff member amongst these services was a physiotherapist hired by the Stroke Support Club for one hour each week. Even among the HACC funded services the numbers of volunteers outnumbered paid staff, although the proportion of total staff hours worked by volunteers amongst these services, approximately 36 per cent of the total, was considerably less than amongst the day centres operated by independent community groups.

## 9.4 Summary

Although now brought together under the one program, day care and domiciliary support services each had a rather different developmental path in Broadleigh. The infrastructure of community support services in Broadleigh developed steadily over the three decades and by the early 1990s provided a fairly comprehensive range of specialised services for those who require support to remain at home. But it is clear that the process of service development, which owed much to initiatives taken within the Broadleigh community, was also shaped by developments outside the local community.

We continue with our discussion of the way services operated in the following section.

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# 10 Organisational Aspects of the Operation of Services

As elsewhere in Australia, community support services in Broadleigh were developed to provide services on a small, domestic scale. Because of their small scale and innovative approach to service provision they were commonly regarded as alternatives in other ways to the larger scale more impersonal forms of traditional provision such as residential care. Yet their form of organisation and mode of operation differed considerably from that of informal care provided in the home, which, as we have seen, was characterised by a highly personalised and flexible system of social relations and support. As much as the home was held as an ideal, community services remained, at best, a form of outreach from the public world of organised work into the private world of the domestic household.

As discussed in Section 1, sociologists such as Litwak (1985) and Kendig (1986) have argued that the structure and organisational characteristics of formal services are essentially different from those of households, families and informal social networks. These characteristics, according to Litwak, ensure that community services and families undertake different and complementary roles in the field of long-term care, and are a major factor influencing decisions to request help from either formal agencies or informal caregivers.

Community support services in Australia were developed in a way that is quite deliberately different from most large scale, traditional services. Their small scale and local often community-based management was believed to enable them to be more flexible and personal than traditional services. But how does this work in practice? How do services operate and how does this effect the way they provide assistance? To better understand the organisational and financial constraints which determined the way services performed their work we discuss a number of the key operational characteristics of community support services in Broadleigh. The discussion focuses on four interrelated aspects: the organisation of service delivery; gender, professionalism and the division of labour within agencies; the mechanisms of service funding; and the objectives and philosophies of service provision.

## 10.1 Patterns of Service Delivery

As we have shown in the previous section, perhaps the most characteristic feature of the organisation of community support services in Broadleigh was the specialised division of labour between services. As elsewhere in New South Wales and other parts of Australia (HACC, 1989; Healy, 1993), there was no single

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organisation which directly supplied all of the different types of assistance likely to be required by those who need help to remain at home. The development and operation of community support services contrasts in this way with the large scale, comprehensive and multidisciplinary services provided in hospitals and nursing homes in the way a range of different kinds of assistance are made available (Friedson, 1963; Croog and Ver Steeg, 1972; Fine, 1986). The division of labour required to provide a comprehensive range of services to those who remained at home was, in consequence, a division between a series of specialised organisations, not within them.

For each new set of tasks identified as necessary for the maintenance of people in the home, a new organisation was created. As local community activists attempted to expand the range of assistance available in Broadleigh, usually in response to new funding programs implemented by the Commonwealth or State Government, the result was an additive or layering effect, with new services being added on top of the existing ones. Rather than reforming and expanding existing services, a series of new organisations were established under a range of different management bodies, differentiated in terms of the geographical area they covered as well as the kind of specialised assistance that they provided.

Nevertheless, while community services differed in this and other ways from traditional, large scale institutional care facilities, so too were there a number of characteristics which distinguished their mode of operation from informal care. For clients at home, these were perhaps most readily apparent in the way that assistance was provided in the home. A number of characteristics stand out.

First, most services operated only on weekdays, providing assistance only during working hours, that is between 8 or 9 a.m. and 3 to 5 p.m., depending on the service. Assistance in the evenings, at night or on the weekend, was only available from certain select services, and then only in exceptional circumstances. Second, most of the assistance provided was task specific, with staff undertaking only a narrow range of relatively specialised activities during their visit. A third, and closely related characteristic was that most of the assistance was provided only during a short visit, with the worker attending the home with the sole purpose of completing an agreed set of tasks. This approach, with few exceptions, precluded the longer stay, companionable form of support that might be provided by a co-resident family member or a domestic assistant. It was also difficult under these conditions, for visiting service personnel to deviate much from their rostered tasks and timetable.

A fourth important characteristic is associated with the assignment of field staff, who assumed an instrumental, rather than a personal relationship with their clients. Personnel who actually provided assistance did not usually have a long history of

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personal contact with the recipients. Personal contact did not commence until referral to the service and even then, agency personnel were often interchangeable. Assistance, for example, was seldom provided by the person responsible for conducting the original assessment. Finally, rather than help arising from a long standing personal relationship, clients were liable to be charged a fee for the assistance rendered. As discussed in the previous section, the charging of fees varied considerably between services, and was not applied universally. The real or potential capacity of services to charge clients for the assistance provided, nevertheless, served to clearly distinguish the formal assistance provided by services from informal care received from family or friends.

To illustrate these characteristics, it is useful to consider the day-to-day working arrangements for the delivery of services among a number of different organisations.

Meals on Wheels services relied on a large roster of volunteers to deliver meals each weekday. The largest Meals on Wheels service in Broadleigh, for example, reported that on average, 220 meals were prepared and delivered on any one day. The delivery of these meals was organised into 11 different runs. Each delivery was organised so that it could be carried out by different personnel each day, most of whom lacked formal qualifications for the work. Approximately 22 volunteers, organised into 11 teams of a 'driver' and a 'runner' (the person who leaves the car and delivers the prepared meal to the client at home) were required each day to deliver warm meals between the hours of approximately 11.30 a.m. and 1.30 p.m. The volunteers changed daily, according to a weekly or monthly roster. A client at home could encounter as many as 20 to 25 different teams of volunteers each month. Volunteers could not, under these circumstances, remain long with an individual client, as any delay meant that subsequent clients on the run would be kept waiting and their meals become cold.

Among Home Nursing services a slightly different pattern of service delivery was encountered. A major feature of their operation was the staff rostering system, which set out the daily allocation of staff. In the nursing service in one municipality, staff were rostered to work for periods of three months in one of five different neighbourhoods, before being rotated to another. In the neighbouring municipality, staff worked on one of three different teams. One team was assigned to the inner area of the municipality, one to the outer area, and the third was a team of two nurses who attended clients unable to be cared for by a nurse on her own. Nursing staff were rotated between these teams each week. Although different, the pattern of staffing in each nursing service was designed to ensure that nurses in the team could, in an emergency, replace each other, as clients were not matched to one single staff member. Over time, staff members could also anticipate some variety in their workload. Nursing staff from the Community Health Centre team,

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in contrast, tended to return daily to the same client, unless there were good reasons (such as sickness or a strong personality clash between the client and nurse) to change.

Like the Community Health Centre team, branches of the Home Care Service of NSW also assigned a single worker to each client. This arrangement was usually only varied if the staff member resigned, if the client requested a change, or if the workload was so intense or so varied that a single field worker could not manage on her own. Home Care branches, however, maintained a sharp distinction between field staff, who provided direct assistance, and service coordinators who were responsible for conducting assessments, allocating staff time and deciding on fees. It was reported that each field coordinator could be responsible for as many as 100-200 clients, including new referrals. Although it was the Home Care Service's policy to reassess clients at regular intervals, the pressure of continually assessing new applicants and the large number of clients assigned to any one coordinator meant that service provision tended to remain unchanged for long periods. In 1993, for example, one of the Home Care branches in Broadleigh reported that it was often more than a year before a client could be reassessed and the assistance provided adjusted to suit.

Coordinators from the Community Options service maintained direct contact with their clients far more regularly, enabling them to make arrangements to adjust the care provided far more frequently. The tasks of assessment/coordination and the direct provision of assistance, however, remained separated in a similar way to that of the Home Care Service. Community Options coordinators were responsible for conducting assessments, organising a package of care for each individual they accepted and monitoring their progress on a regular basis. They did not, however, normally provide assistance directly to clients. This was instead the responsibility of staff members from other community support services that accepted the referral, or employees of private agencies specifically contracted for the job.

The program of activities was also generally highly routinised in day care centres, as discussed in the previous section. So too was the division of duties between the coordinator, volunteer day staff and the driver generally quite distinct.

The pattern of service delivery developed by the Dementia Visiting Service perhaps most closely resembled that of households. Each client of this service was assisted by a single staff member, who visited each weekday for a period of approximately two hours. The visiting staff member was assigned to undertake whatever variety of different tasks was required by the client, which in some instances was reported to be companionship, in others possibly cleaning, shopping or assistance with cooking. The type of assistance provided was also likely to vary between clients, and, with the one client, to vary somewhat on a daily basis. But even here a

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distinction was made between the tasks of the service coordinator, responsible for accepting the referral, conducting the assessment and allocating staff assistants, and those of the field staff who actually provided the assistance to the client.

## **10.2 Gender, Professionalism and the Pattern of Staffing**

- One of the more striking similarities between domestic work at home and the work performed by community service staff was that in both cases most of the work was undertaken by women. Women not only constituted the majority of paid staff but in most services were also the majority of active volunteers. Although retired men were reasonably well represented in voluntary work, they were typically confined to jobs such as driving vehicles, which are regarded as traditionally masculine in orientation. Male employees in most services were disproportionately concentrated in senior or managerial positions. Men were also well represented on Boards of Management of virtually all community based organisations. The only service in which male employees were actually in the majority was the Home Maintenance and Modification Service, where they worked as carpenters, handymen and builders under the direction of a female coordinator. In all other services female employees predominated.

The association between women with formal community care services is not, of course, unique to the Broadleigh region. The tasks involved in supporting people to live at home are, in many cases, typical of domestic caring tasks and the employment they represent is often sought after by women returning to the workforce after a period of absence due to child rearing. Work calling for professional qualifications, such as nursing, social work and paramedical therapies, are also fields in which the most suitably qualified personnel are generally women.

It was, therefore, not surprising that the availability of employment in the local area in Broadleigh, providing assistance often on a part-time or casual basis to people who remained at home, was often considered convenient by women who continued to have to balance employment with domestic responsibilities. But it is unlikely that it was simply because the work was often sought by women, or because women were held to be more competent or more likely to possess desirable personal qualities such as patience and compassion, that the association of community support with women was so important for the character of community services.

As Neysmith (1991) and others have argued, the working conditions, pay and career prospects encountered in the field of community services mark it out as belonging to a specialised female labour market. The characteristics of this market derive from the fact that work is predominantly performed by women who lack industrial power and often have few other attractive options for work. Their jobs

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are frequently undertaken in cooperation with, and to an extent in competition with women volunteers and male retirees, undermining their capacity to gain full social or economic recognition for the full worth of their skills and commitment (Baldock, 1991). The strength of claims to the development of careers which could help lift their recognition is also limited by the extent to which their work is seen as more of a compassionate, even charitable mission, than as a job.

### The Division of Labour

An important feature of the delivery of assistance by community services concerns the division of labour among service staff. Based in part on the gendered division of labour in the provision of formal care, but to a far greater extent on the structure of employment and responsibility required in formal settings, the pattern of staffing in many services reflected a division of activities into coordination/management tasks, often, for example, combining the assessment of clients with the management of other staff. Routinised direct-care tasks were then performed by lower level direct service personnel. This type of staffing pattern in one way provided considerable flexibility, permitting the use of a high proportion of part-time workers in direct service roles and facilitating the ready replacement of one service worker with another to meet the requirements of the roster. The more experienced, most highly qualified and longest serving staff tended to be concentrated in management positions. This arrangement allowed for some standardisation of tasks and was robust enough to be able to withstand a relatively high turnover rate amongst those often less qualified staff members responsible for direct service to clients. However there was often relatively little opportunity for lower level staff to influence the way services operated, as their direct service provision role limited their capacity to develop a comprehensive perspective of the organisation's operation. Further, the need to standardise tasks so that they could be undertaken during restricted work hours by different staff members also tends to limit the capacity of the organisation to adjust the assistance offered to suit the individual needs of different clients.

Care was, therefore, produced through a division of labour similar to that found in large bureaucracies and mass production facilities.<sup>35</sup> This is not to say that there

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35 In the household, few could deny the traditionally gendered division of labour, with most indoor tasks, such as cooking, cleaning, washing, shopping and personal caregiving, being regarded as female tasks, and outdoor tasks, such as lawn mowing, and household repairs and maintenance being undertaken by males. Within this gendered division of labour, however, there was considerable flexibility. Many women, for example, undertook a variety of different tasks, such as cooking, cleaning, providing personal care, shopping, driving the car, banking and so on. Recent changes in the sphere of industry also point away from traditional patterns of trade specialisation towards more flexible,

was not a strong commitment amongst managers and staff to provide assistance in a personalised and caregiving manner, nor to deny that close personal relationships often developed between service personnel and clients. But in each of the services surveyed a significant qualitative difference was recognised between the relatively flexible working arrangements encountered amongst families in domestic settings and those promoted among community support services.

Community services are formal organisations. Despite the small scale of many services and the highly personalised nature of their work, they operate according to a legally documented constitution, with clearly defined decision making procedures and conventions for the exercise of accountability. Their operation in Broadleigh, as elsewhere, was required to ensure that provisions for staff to industrial entitlements such as paid vacations, workers compensation and sick leave were honoured. These, and other requirements for legal accountability ensured that all but the purely voluntary day care services were influenced by bureaucratic considerations in their structure and administration. Indeed, this bureaucratic tendency in service provision may be inevitable if funds are to be efficiently and accountably used.

Ann Dill (1993) argues, on the basis of a study of community service provision in the United States, that community services operate in a more or less bureaucratic manner because of both their historic origins and dependence on government licensing, and because they have been unable to develop an alternative to the technical logic of bureaucracy. As Max Weber contended earlier this century, bureaucratic forms of organisation have prevailed in the twentieth century because they are simply far more efficient than other forms of organisation.

The decisive reason for the advance of bureaucratic organisation has always been its purely technical superiority over any other form of organisation. ...Precision, speed, unambiguity, knowledge of the files, reduction of friction and of material and personal costs -these are raised to the optimum point in the strictly bureaucratic administration. (Weber, 1978: 973-5)

Amongst the characteristics of an ideal bureaucratic form of organisation, according to Weber, are established hierarchical lines of authority with a functional division of labour along specialised lines; the methodical allocation of duties according to

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multi-skilled working arrangements (Hoggett, 1990). The organisation of the workplace has, at least until recent times, been characterised by a division of labour along the specialised lines of the (Henry Ford inspired) mass production workline. This industrial approach is often associated with the school of scientific management, commonly referred to as Taylorism (Braverman, 1974).

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training and function of the official (rather than on the basis of personalised ties such as kinship or the individual disposition of the official); the development of clearly defined procedures (rules and regulations) for the ordering of transactions; the keeping of records; the 'objective discharge of business ... without regard for persons'; an emphasis on efficiency in the performance of work; and a protective attitude of administrative secrecy by the organisation to 'hide its knowledge and action from criticism as well as it can' (Weber, 1978: 956-1003).

These attributes constitute the technical means by which organisations can operate most effectively, particularly in environments, such as the HACC Program, where reliability of provision is essential, and in which organisations are responsible to government for the performance of their duties. Paul Hoggett (1990) has shown that despite the significance of recent developments in organisational theory and practice promoting the flexibility of labour and a reduction in the scale of decision making hierarchies, most effective organisations, whether operating as part of government, as a private company or as a non-profit service, continue to rely on these basic techniques of organisation in one form or another. This is despite the fact that, newer forms of organisation, like many community support services, are undoubtedly more flexible, less organisationally complex and less bureaucratic than traditional formal organisations.

Another important feature of community support services is the division of labour along professional and semi-professional lines and the emergence of professional rivalries both within and between services. Rivalries between services due to their professional orientation also been reported in other recent Australian studies of HACC services (Yeatman, 1990; Healy, 1993).

One reason for the prominence of professions and semi-professions in Broadleigh is the nature of the work, which in many respects is closely related to health care. Many of the services were essentially paramedical or nursing in character, and adhere to the professional division of responsibilities which dominates this form of work (Willis, 1983; Palmer and Short, 1989). As many of the tasks (such as medical assessment, the care of wounds, and the administration of injections and medications) involved in providing community support often require a knowledge of nursing or medical matters, it is not surprising that suitably qualified personnel claim this sphere as their own, in some cases disputing the capacity of others to undertake the tasks. In turn, elements of their work may be identified which did not require any specialised nursing or medical training. These have been readily seized on by others as tasks which should not be carried out by professional staff.

The identification of particular services with a single profession is exemplified in the case of the home nursing services. In interviews and at several meetings we attended, Directors of Nursing as well as other nursing staff took the opportunity to

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condemn what they regarded as the unprofessional approach adopted by certain services. One particular issue that they disputed was the provision of personal care by unqualified staff, such as Home Care personnel. Some Home Care staff and managers of certain other services, in turn, were quick to defend themselves, pointing out that their clients were not all sick and did not benefit from the unwarranted medicalisation of care at home. They also pointed out the appropriateness of their interventions, which, they claimed, were based on what might reasonably be expected of a (non-professional) family helper. There was reputed to be a directive from the central office of the Home Care Service of NSW which specified that clients with unstable health conditions were to be referred to the Home Nursing Services. Clients with stable health conditions, including those requiring personal care, were to be referred to the Home Care Service. Codification of this professional divide between service agencies has most certainly helped ease a difficult dispute, but it has also served to entrench the basic division in professional training and approach between agencies with fundamentally different orientations and employment policies.

Such professional rivalries, underpinned by the structure of service provision at the local level and by the administration of the HACC program by a series of different State Government departments, appeared to underlie many of the difficulties experienced in the coordination of different services. Similarly, they also appear to have affected the assessment and allocation of assistance to clients, as discussed in the following section of the report.

### **10.3 Funding Mechanisms**

The mechanisms by which recurrent funding was made available to services by the government represent another important influence on the operation of services and their delivery of assistance. Their influence, which is in addition to the amount of subsidy made available, is particularly crucial for determining the pattern of service allocation to clients.

Because there is a division between the major Commonwealth/State departmental funding bodies and the services which actually provide assistance, it is possible to identify two distinct phases in the budgetary processes by which the assistance provided by services is rationed. First, at the macro-level, the amount of funding provided to services by government determines the total amount of staff hours available. Second, at the micro-level, the assistance is allocated to consumers by service providers. Allocation decisions, with few exceptions, are generally left to service providers who must both operate within the constraints of the resources available and determine the relative priorities for assistance from amongst all those identified as in need.

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With only one exception, government grants under the HACC program involved the payment of an annual subsidy, paid to the service as a block grant. Services were paid a fixed amount each year, regardless of changes in demand or of the number and type of clients assisted. The approach, which involved matching funding to provide care for an agreed 'estimated number of users', is set out in the National Guidelines for the HACC program, reproduced in Figure 10.1.

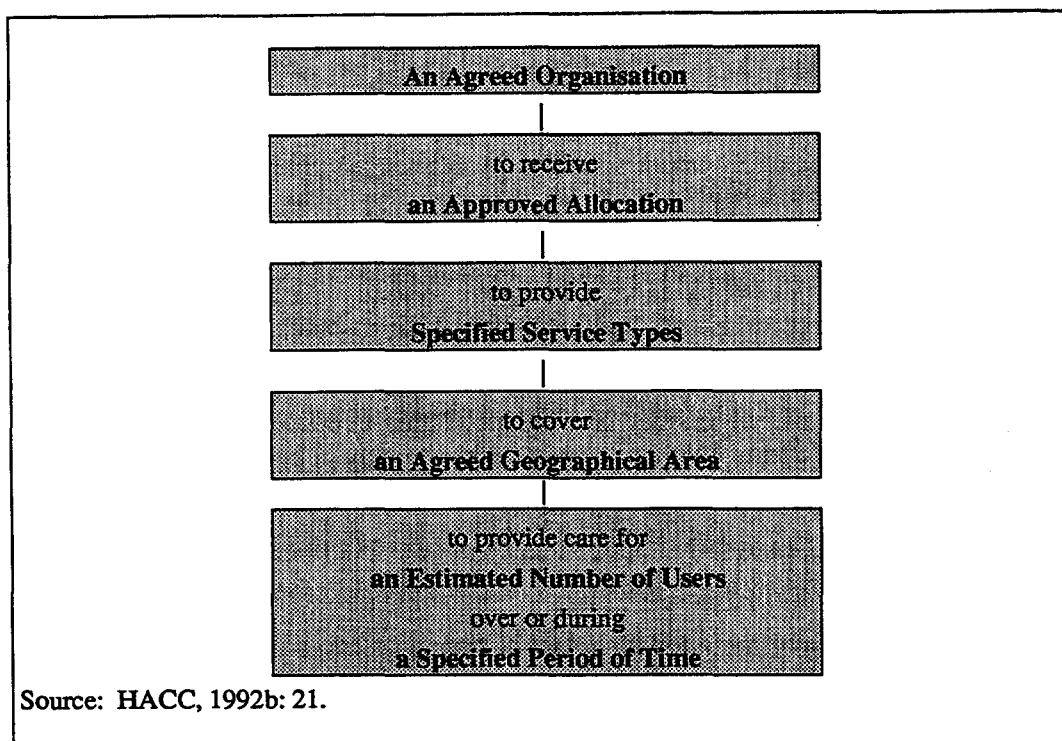
The block funding approach provided funding over a given period of time, usually a year, to enable an organisation to assist their users, the estimated number of whom were usually derived from the experience of previous years. If new and eligible applicants exceeded the estimated number, services were faced with the stark alternative of either attempting to assist them all, thereby reducing the amount of assistance available per user, or refusing to assist them, perhaps placing new applicants on a waiting list until a later date or referring them on to alternative sources of support.

An alternative to the block funding approach is the service linked payment, the funding mechanism used by Community Options Program.<sup>36</sup> With this approach, funding is directly linked to the amount of assistance required by individual clients. To limit total expenditure, a maximum number of clients is specified. For the Community Options Service, the spending limit per client each week was set in 1990 at \$400 per week. The maximum number of clients the service was permitted to assist at any one time was limited by the funding agreement at eighty (Graham, Ross and Payne, 1992). This arrangement enabled the service, through the brokerage and payment for assistance from other HACC agencies and independent providers, to provide considerably more assistance to each client than other services.

While both models of resource allocation impose a form of supply side rationing on services, limiting expenditure for government, responsibility for ensuring that assistance was allocated in the most equitable and effective way to meet the needs encountered in the local community was borne by local agency staff. Unlike pensions and benefits provided through the social security system, applicants seeking help from community support services were not able to make reference to clear eligibility criteria, nor did they have a legally enforceable entitlement to the assistance provided. Nonetheless, if they presented themselves to services and were clearly in need, it was often difficult for the staff of publicly funded services to turn them down.

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36 A variation on this approach has currently been adopted for the provision of Community Aged Care Packages (CACPs), in which a fixed package of care is made available to a fixed number of eligible recipients (DHHLGCS, 1993a: 122-4).

**Figure 10.1: Funding and Approval Process of HACC Services**

## 10.4 Service Objectives and Philosophies<sup>37</sup>

The objectives of services provide a further important insight into the way services operated. Service objectives, which concern what is variously referred to as the goals, aims or mission of an organisation, provide a rationale for the services' operation as well as serving as a guide for decisions about the allocation and delivery of assistance to individual clients.

We asked service managers the question *'What do you see as the main purpose of your service in providing assistance to people who remain at home?'* The divergence of service objectives described by the personnel of different services is quite striking.

Several managers reported that the main objective of their service was to prevent admissions to nursing homes, providing clients who wished to remain at home with

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37 This discussion draws on the series of in-depth interviews with the managers/coordinators of 11 different services in Broadleigh which were conducted towards the conclusion of the study. The methodology is outlined in Section 2.

an alternative to institutionalisation. Echoing the official objectives of the HACC program, the manager of one of the branches of the Home Care Service of New South Wales, for example, answered:

(Our objective is) preventing premature or inappropriate institutionalisation, keeping people living in their own home independently for as long as possible. ... Life in a nursing home is shocking, there's no dignity in that. People should be in their own home.

Other service managers, also dedicated to providing an alternative to institutions, spoke of the purpose of their service being to provide consumers with a choice. The coordinator of the Dementia Visiting Service, for instance, said the purpose of her service was:

To allow people dignity and independence and the choice of staying at home. We try to help people to stay at home if they want to.

The purpose of the Community Options service was described by its coordinators in broadly similar terms.

To give them the choice to stay at home, or accept admission to an institution. If they want to stay at home (we aim to) ensure a reasonable quality of life.

The managers of most of the older, first generation, community services, however, took a more modest view, seeing their service as part of a spectrum of care, working together with family members to supplement, rather than provide an alternative to, nursing homes.

(Our purpose is) to provide sustenance to keep them alive. I think everyone should have the option of staying at home, but people who need nursing homes should use them. (Coordinator of Meals on Wheels service)

We aim to maintain their independence and to keep them in their own homes. But we can't help people who need nursing home care on our own. There are borderline cases (where) we are dependent on family support. (Director of Municipal Home Nursing service)

In some instances, it seemed, service staff were sympathetic to the ideals of providing a choice to life in a nursing home, but quite deliberately encouraged people to use nursing homes when they felt they could no longer guarantee to provide adequate support.

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(We aim) to allow them to stay in their own environment and to choose what they need. Most of the time we help keep people at home even when it's not best for them any more. But we do encourage them to understand their own situation and assist them to decide to go into a nursing home if necessary. (Director of another Municipal Home Nursing service).

In a number of such instances it was clear that while service coordinators felt it necessary to recognise the widely held ideals of community care, using the language of the HACC program of providing a 'choice' to clients, they did not feel their service was capable of offering sufficient support to provide a realistic alternative to nursing homes for clients with a high level of need.

While most coordinators spoke of the general principles of providing support, sometimes the aim of service provision was stated in quite concrete terms, as simply the provision of the particular form of help provided. The Meals on Wheels coordinator, quoted above, for example, saw 'the provision of sustenance' as the main purpose. Similarly, the Day Care coordinator spoke of the purpose of her day care centre being to

Give them social contact, and the ability to get out and have social contact and recreation. ... Another aim is respite for carers.

The absence of a common sense of purpose between the different services is indicative of the fragmented provision of services described in the previous section of this report. It may also reflect the fact that some of the older (first generation) organisations developed at a time when nursing homes were the main forms of provision and community services were intended simply to provide a limited amount of assistance to those who remained at home and did not require extensive help. More recently established services, owing their existence to the HACC program, tended to endorse the programs' objectives by attempting to provide an alternative to admission.

The service objectives identified in each of the coordinators' responses also reflected the different operating conditions experienced by each of their services. In the case of the Home Care Service of New South Wales, for example, statewide policy in the 1990s has been to direct resources towards clients with a high level of needs who are most at risk of institutionalisation, even when this requires resources to be diverted away from others who need support but at a lower level. Similarly, the Community Options service was specifically established to provide care to a limited number of people at risk of institutionalisation. In both cases targeting decisions, made at the macro-level by senior program administrators and politicians, were reflected in the operational philosophies of local service coordinators. Considerable effort was made to ensure that the resources were available to realise these goals.

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In contrast, neither the Meals on Wheels service nor the Home Nursing services had sufficient resources to meet all requests for assistance, let alone the capacity to increase their allocation of assistance flexibly to meet the significant demands likely to be placed on them if they were to take responsibility for supporting a significant proportion of clients in need of support at the level of intensity available in nursing homes.

### **Independence, Dignity and Privacy**

Equally important were the service managers' interpretation of the philosophies of respect for the independence, dignity and privacy of clients which, as will be recalled from the discussion of the objectives of the HACC program in Section 1 of this report, are key values underpinning the policy of community support. These rather abstract principles were reflected in the operational philosophies of community services in Broadleigh in interesting and often contradictory ways.

Virtually all service providers, for example, emphasised the importance of encouraging independence for clients when making decisions about the type and amount of assistance clients should receive. When determining the amount of assistance a potential client would receive, it was considered important to maintain respect for, and in some cases to nurture, the client's independence.

This theme, which emerged strongly in the discussions of the case studies presented in Section 8, was articulated particularly clearly by the Director of Nursing of one of the Municipal Home Nursing services when responding to a question about how they decided how much assistance different clients should receive.

We don't like people to be dependent on the service, and frequently have to wean people off us. We encourage people to be independent ... our whole basis is to maintain the independence of people at home. We step away one day at a time until they get confidence. It also works in reverse, and sometimes we need to step in a little at a time.

Staff of the Aged Care Assessment Team similarly reported that

Many people see giving up what they do as the first step to a nursing home. People do not want to lose their independence and it's often difficult to get them to accept help at all. At the same time, it's also important to encourage people to maintain their independence, or to learn how to regain it. That's why we have to be careful not to try and make people dependent on help from services if it's not absolutely necessary.

Support for the principle of independence was, thus, used as a rationale for intervention for those who required support, as a reason for withdrawing from providing help when it was required temporarily as part of a process of recovery or

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rehabilitation, and as a justification for limiting the amount of assistance that could be provided.

The rather delicate balance that was sought between encouraging applicants to maintain their own capacity to look after themselves as far as possible and providing appropriate support to those who required it, was expressed by the manager of one of the Home Care branches as follows:

It's basic maintenance only that we provide. We are not there to take over. They have got to have some independence. We won't do it if they are capable of looking after themselves. They will be independent, even if they don't want it.

Supporting the independence of clients at home represents the endorsement of a normative cultural value, which appears to have a broad popular appeal throughout Australian society, as it does in a number of comparable countries.<sup>38</sup> Importantly, the exercise of independence is also an ideal which has considerable significance for those who require assistance in order to remain at home, a fact cited by service providers as contributing to people's reluctance to accept services. Many of the participants in this study, indeed, argued that accepting more help from services than they received would have been an admission of their dependence, and have demonstrated their incapacity to continue to maintain a degree of independence in their lives at home. One participant living on her own, for example, when asked her attitude towards receiving help at home, stated that:

I'm glad to have it but it makes you feel a bit low ... as though you are receiving charity. You feel that you're on a downward path ... more dependent, not independent. You don't want to feel that you can't manage.

Another, who was only capable of remaining at home with help from his wife, answered:

If I had to I'd receive it graciously, but I wouldn't be happy about it. You should rely on yourself.

Closely paralleling the emphasis on promoting respect for the independence of clients, many service providers also stressed the value placed on respect for the client's right to privacy at home. Again, the staff of one of the nursing services argued that

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38 There has, for example, been a long-term debate in the field of gerontology arguing that older people are not as dependent as is widely believed (Munnichs and van den Heuvel, 1976; Gibson, 1985).

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People living at home are the keepers of their own castle. We have to be careful not to intrude. If coerced they will drop out. ... We're here to support them, but you can't force them.

Another reported similarly:

We need to know our boundaries, we're guests in their homes.

Services providers thus reported that they respected the client's right to accept or refuse assistance in the home. Several co-ordinators explained they had learnt that unless clients and their caregivers wanted help, there was little point in providing it. While this principle had the benefit of enabling clients to select their own package of services, in practice it appeared that respecting clients' choices often meant that (potential) clients were given the opportunity to refuse assistance or only to receive such assistance as was offered.

## 10.5 Summary

The operation of community support services in Broadleigh must be understood as having much in common with other small scale formal organisations. Given limited resources and a formal charter which encouraged personnel to ensure that the assistance provided maximised the benefit they provided for clients, their operation was inevitably constrained by a range of structural and ideological factors. A number of these were considered in this section, including the division of labour within and between organisations, the staff rostering arrangements, the influence of professional ideologies, the relatively weak industrial position associated with a predominantly female workforce and, importantly, the funding arrangements associated with block grants. In the following section we pursue these themes, examining how the operational characteristics of services interacted with the expectations and demands made by clients and potential clients to influence the allocation and use of services.

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# **11 Mechanisms for the Use and Allocation of Services**

As discussed in Sections 9 and 10, research with the community support services in Broadleigh revealed an infrastructure of provisions which manifests its recent history of unplanned and incremental development. In the absence of any mechanism for systematic coordination, a range of specialised service agencies operated with a high degree of autonomy. Funding increases in recent years enabled the range of services to expand, but the funding and administrative arrangements continue to foster and reinforce the sense of each service's autonomy just as they limit the amount of assistance each can provide to clients.

Evidence presented in earlier sections also showed that although participants who remained at home received only modest levels of assistance from formal services there were relatively high rates of admission to residential care. Participants expressed a desire to maintain their independence, a strong attachment to their own home and were reluctant to consider moving. These sentiments were also shared by caregivers. Associated with this was a relatively modest expectation of assistance from services and a correspondingly low level of use of formal provisions.

The provision of formal assistance to people in their own home takes place within a larger system of government policy and funding, over which those in the local community have little direct control. With only limited resources at their disposal, the staff of community support services must interpret broader policy objectives and develop practical strategies which enable them to identify and assist those most in need. By establishing priorities and guidelines for the allocation of assistance, these strategies seek to balance the demand for assistance from the local community with the limited resources available.

The main strategy employed by community support service staff was what we have called 'passive intervention'. This approach, which embodied many of the core values associated with the policy of community care - including the promotion of the clients' independence, support for their right to choose how they lived and respect for their privacy - was a practical and viable strategy which enabled conscientious and hard pressed service providers to reconcile the many contradictory demands under which their organisations operated.

In this section we draw together evidence collected from both the providers and consumers of support to examine the process by which clients and potential clients

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gained access to the assistance provided by formal community support services as they operated in the Broadleigh region. Information from the 60 participants in the study and their caregivers, who represent the consumers and potential consumers of services, is used to supplement that provided by service managers and personnel of a representative sample of services in Broadleigh.

Before presenting our own analysis of the processes associated with consumers gaining access to services and with the allocation of assistance by service personnel, we review a number of other studies which have also attempted to explore the same issues.

### **11.1 Perspectives on Community Service Use**

Confirming the results of this study, a number of other researchers have also reported evidence of low service use by people who are supported at home and require assistance to remain there (Chappell, 1985; Smallegan, 1985; Clark et al., 1987; Litwin and Auslander, 1988; Soldo, Agree and Wolf, 1989; Levin, Sinclair and Gorbach, 1989; Opie, 1991). Typically, the viability of support in the home is seen to be reliant on the efforts of informal caregivers.

Researchers attempting to understand the use of services have tended to approach the subject from one of two positions, representing either the supply or demand for assistance. In many cases research has concentrated on measuring the extent of service use by particular populations, but has lacked a methodology which would enable the investigation of the reasons for this. For example, Colson (1986), who drew on data obtained from three surveys (the Australian Institute of Multicultural Affairs Survey of Aged Migrants; the Australian National University Survey of the Aged; and the Australian Bureau of Statistics Australian Health Survey of 1977-78), found that a much smaller proportion of older people from non-English speaking backgrounds received help from community services than those born in Australia. This was attributed to problems in the supply of services. Other large scale studies, such as those documented in Australia by Howe and Sharwood (1989), Maria Evandrou's account of the use of domiciliary services by the elderly in Britain based on an analysis of information provided by the 1981 General Household Survey (Evandrou, 1987), and research from the USA such as that of Corson, Grannemann and Holden (1988) which analysed the statistics on service use in the Channeling demonstration project, also provide a rich source of quantitative information on the amount of service use and the characteristics of the population of service users. However it is not possible to investigate the links between the structures of service provision and the characteristics of the population using the services using survey data of this kind on its own.

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Studies using a demand perspective often attempt to extrapolate from the characteristics of existing service users. Nina Chappell (1985), for example, used interview data to compare a stratified random sample of the users of community services with a matched group of non-users in Manitoba, Canada. She found that users of the available home care services were more likely to be women, to be aged over 75, to be widowed, to live alone in an apartment, and to suffer higher levels of functional disability than non-users. Chappell argued that the need for assistance (as measured by the level of functional disability and health), rather than the existence of informal social networks, was the most likely basis for the receipt of services under the system of case management found in Manitoba. Other researchers, such as Blieszner et al., (1987) and Biegel et al., (1993) using a similar perspective, relying on statistical evidence of correlations between the characteristics of clients and the use of services, have reported similar findings.

Detailed qualitative studies of the demand for assistance from (potential) service users provide a somewhat different perspective on the use of services. Elizabeth Moen (1978) for example, conducted in-depth interviews with a sample of just 25 elderly people in a rural region of Oregon, identifying what she termed the 'reluctance of elderly people to accept help'. Despite evidence of widespread need for assistance, what emerged from these interviews was the deep seated reluctance of most of the older subjects to accept help from formal services or admit the extent of their needs for assistance (Moen, 1978). A similar methodology was employed by Montgomery and Hatch (1987), who found that families tended to be 'fiercely independent and fail to seek services until arriving at a point of crisis' (Montgomery and Hatch, 1987: 153).

In a recent literature review, Chappell (1994) reviewed a large number of other works on the use of community services by older people, almost all of which, she points out, adopted the Andersen-Newman model of service use which distinguishes predisposing factors (such as age), and enabling factors (such as income and the accessibility of referral agents) from need factors (including disability and health) (Andersen and Newman, 1973; Wolinsky, 1978). Given this frame of reference, explanations of the level of service use are largely confined to the factors associated with an individual's usage of existing service provisions. While this approach has proven insightful, it can not adequately account for the way supply affects use, nor explain how decisions affect the allocation of services to individual clients, or examine the reasons for non-use of services by those in need.

One alternative approach uses field based research to combine the study of the demand for assistance with the provision of services. Quadagno et al. (1987) for example followed a group of people referred to Medicaid agencies in Kansas. It was found in the follow up interviews with clients and caregivers that although they

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reported a high level of satisfaction with the assistance provided, the care plans prepared relied on informal support and only a minimal level of assistance from formal services had been received. The authors argued that because the recipients of assistance were 'powerless individuals with few alternatives to those offered by the bureaucracy' (Quadagno et al., 1987: 127) caution was needed in interpreting the results of their study. In a similar study of 'unmet need' associated with the 'underuse of services' in Pimlico, London (Chapman, 1978) an action research methodology was used to facilitate access and stimulate the expression of demand for assistance. It was argued that the demand for assistance from community services was closely linked to supply. Without pressure to induce demand, it was argued, the supply of services remained restricted. Another link between supply and demand was expressed colourfully as 'shoddy goods will not attract buyers' (Chapman, 1978: 66). Other problems identified included limited and difficult access to services, the complex and often stigmatising administrative processes associated with service access, and the refusal of some people to accept the help offered.

More recently, in Australia, Judith Healy compared the use of community support services in Adelaide and Melbourne. She found that quite different packages of care were provided to samples of older people with similar patterns of need in the two cities. Not surprisingly, she concluded

These Adelaide and Melbourne localities allocate very different community services to similar people. Each service field has developed its own infrastructure and culture which determines the resources tapped from the Home and Community Care program and the way in which clients are assisted. Thus the structure and traditions of each field determine the assistance that people receive as much as national policy and client need. (Healy, 1994: 53)

An even more ambitious study, conducted by Hunter, McKeganey and MacPherson (1988) in two health regions in Scotland involved the comparison of two regions with contrasting mixes of provision to 'document and understand the interaction between services and older people'. They found that variations in patterns of service use between areas were predicted more by the differences in the organisation and patterns of professional staffing of services than by differences in the need for help. However, despite differences in the use of services, it was not possible to document significant differences in the outcomes for consumers.

Research on the provision of home care services in Britain by Davies, Bebbington and Charnley (1990), was more focused and conclusive. A large study conducted over three years and covering home care in twelve separate regions of England and

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Wales found that there was little correlation between the needs of services users and the amount of assistance they received. The authors argued that as additional funds had become available to the services in the 1970s and 1980s, they had been used to extend coverage. The increased coverage limited the capacity of services to provide more intensive levels of assistance to those who required it. The study found that most assistance was provided in fairly standardised amounts despite the emphasis placed on assessment by most service managers. Most applicants, regardless of their level of disability or living circumstances, received around two hours home help a week. Reassessments were far too infrequent to enable existing resources to be redirected, over time, to clients with higher needs.

A somewhat more modest study conducted in Groningen, the Netherlands (Hadderingh et al., 1991) was established to 'catalogue' a series of problems encountered in the care of dementia patients. The research employed a qualitative methodology based on the analysis of 50 case studies of individuals initially referred to a particular service (the RIAGG). Interviews were conducted with the client and their caregiver, and questionnaires completed by the clients' medical practitioner, the RIAGG staff, and personnel from home help services, home nursing and day care centres responsible for their case. It was found that the different services had often given contradictory advice and made a series of uncoordinated arrangements to support the family. Most importantly, it was shown that perceptions of need differed considerably amongst individual services and their clients and informal caregivers.

Complementing perspectives on the supply and demand for services, is a third line of research concerned with the mediating role of professionals as referral agents or gatekeepers to the system of long term care (Roos, Shapiro and Roos, 1984). The recent summary of research by Sinclair and Williams draws together a wide range of studies concerning self-referral and referral by general practitioners, social workers, hospitals, and others. The authors conclude that:

The allocation of statutory services is in the hands of professionals. Old people and their relatives may refer themselves for services but in the case of most services they do this infrequently. They may also argue their case for a service or refuse to accept it. They do not, however, have the final say in allocation. (Sinclair and Williams, 1990: 157)

Recognition of the extent to which unrestricted referrals from general practitioners led to the overuse of nursing homes was one of the main reasons for the introduction of Geriatric Assessment Teams (now Aged Care Assessment Teams) throughout Australia since the early 1980s (DHHCS, 1991a). Other research on mediating factors has pointed to the lack of knowledge of service provisions

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amongst older people (Gibson, 1984) and to the critical role of informal networks as facilitators of service use (Krout, 1983; Noelker and Bass, 1989).<sup>39</sup>

In short, research conducted from a number of perspectives, using a variety of different methodologies, has shown that a range of factors affect the use of community support services. Evandrou summarised these concisely:

The issue of the determinants of statutory service use amongst the elderly involves a complex interrelationship of three different agents; the elderly persons themselves, the carers, and the service providers. ... Judgements of need for services are made by service allocators and professionals, according to various factors. However, the criteria employed in resource allocation decisions and the assumptions made about the availability of care from within the elderly person's household, are never made explicit or documented in any systematic form. Yet it is such mechanisms within the service provision process which require exploration and detailed study. (Evandrou, 1987: 33)

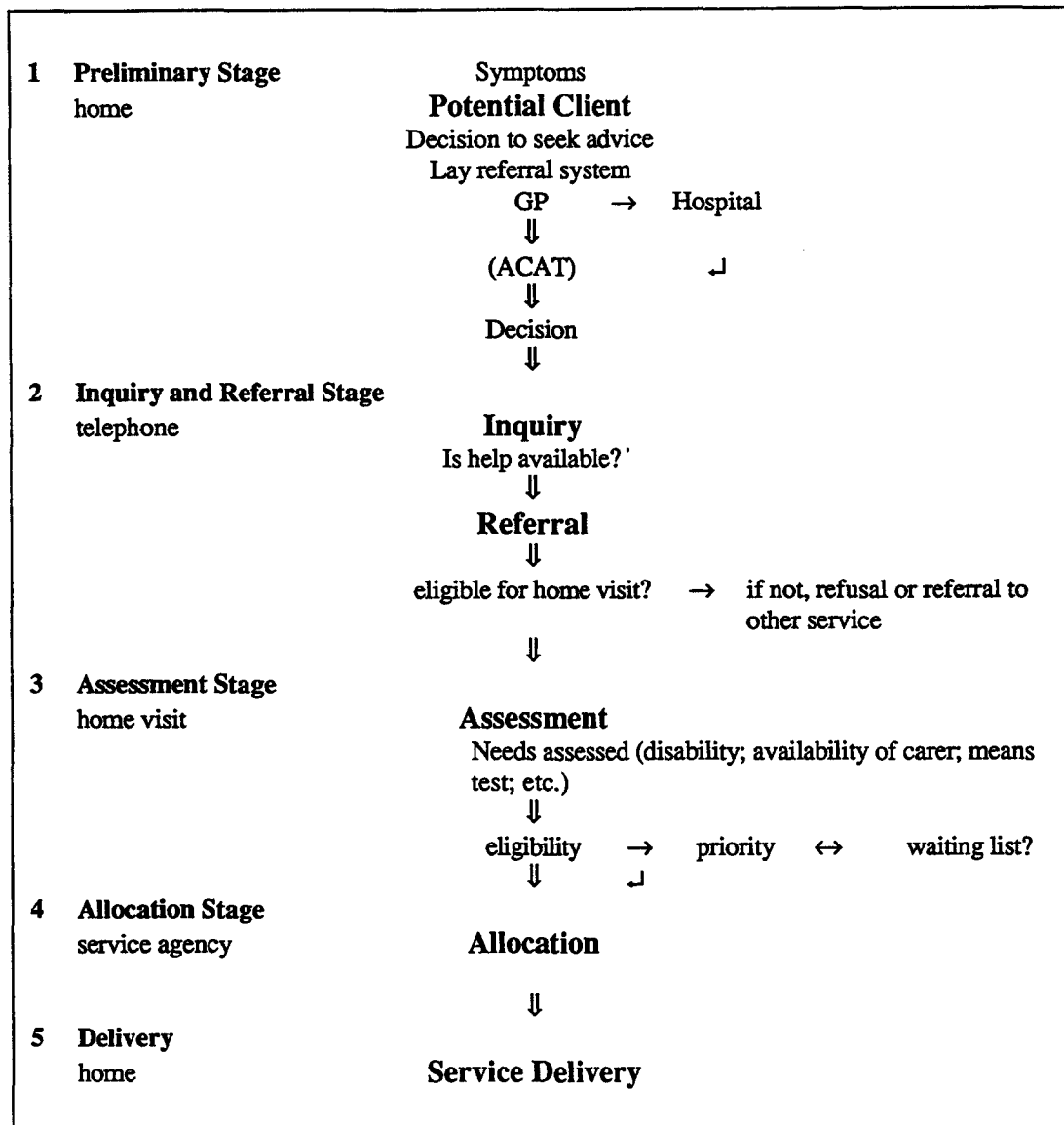
To explore these mechanisms at work in Broadleigh we turn now to consider the process by which clients and potential clients sought to gain access to community support services.

## 11.2 Pathways to Assistance: The Service Allocation Process

Potential clients gained access to community support services through what we have termed the 'service allocation process', which operates within a much larger social context bounded by government policy and funding arrangements on the one hand and by the interaction of the individual in need of assistance with their informal social support network on the other. Following an approach developed by the medical sociologist Irving Zola (1971; see also Tuckett, 1976) a potential client's pathway to a service may be thought of as commencing at a preliminary stage involving the emergence of an awareness of the need for help, before entering the inquiry or referral stage. For those who subsequently gain access to services this is also followed by the assessment, allocation and consequent delivery stages (see Figure 11.1). Within this process a set of procedures have developed through which services are allocated. Drawing on both the accounts provided by service

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<sup>39</sup> There is also an important debate about the possible displacement of demand for formal assistance by informal caregivers (Cantor, 1989; Litwak, 1985) discussed elsewhere in this report.

**Figure 11.1: Client Pathways to Community Services: A Schematic Representation**

providers and those of participants and their caregivers, we have identified a series of distinct steps which need to be taken by, or on behalf of, potential clients before decisions are made about any assistance they might actually receive.

### Preliminary Stage

Access to services begins in what we have called the preliminary stage. This occurs when the potential client is at home and symptoms of a physical or



cognitive/behavioural incapacity appear which necessitate assistance. Before it is possible for any assistance to be provided, the person must decide on the next course of action; either to ignore the problem, deal with it themselves or seek advice from others.

This process, which involves the detection of symptoms and a subjective weighing up of the advantages and disadvantages of speaking up and informing other people about a possible problem, reflects what medical sociologists, following the work of David Mechanic (1968), have called 'illness behaviour'. Illness behaviour refers to the 'activities undertaken by a person who has symptoms in order to define the state of his [or her] health and discover a suitable remedy' (Tuckett, 1976: 166). Cultural, social and economic factors, as well as an individual's gender and personality, are likely to be significant influences on the preparedness of different people with similar symptoms to begin to seek assistance.

Having decided to share their thoughts, the first source of advice is usually members of the family or friends, a stage in the identification of illness that Friedson has termed the 'lay referral' system (Friedson, 1963). Members of an individual's lay referral or support network may then offer direct assistance, or, as a result of their counsel, take steps which lead to contact with a particular community service. Alternatively the person may contact their GP directly. The GP can then take action such as offering advice and giving information about seeking further help, placing the person in hospital, referring them to an Aged Care Assessment Team or directly to a community support service.

The lay referral system appeared to be of particular significance for participants in the study, and applied even in perceived emergency situations. In the second stage of the study participants and caregivers were asked the following open question: *If you did have to ask for help in an emergency (say you could not get out of bed) who would you turn to?* Forty of the 45 participants claimed they would seek help first from caregivers, family, neighbours or friends before turning to more formal sources such as emergency services or a doctor. No response was recorded for four participants. Only one person indicated they would first seek help from emergency services.

The responses of some of the participants give an indication of the thinking behind this approach.

*If you did have to ask for help in an emergency (say you could not get out of bed) who would you turn to?*

My next door neighbour, Mrs P. She also has my brother and sister's phone number and all the Vitalcall business and the

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keys to my unit. She'll know what to do if necessary. (Mrs Dawson)

Oh I suppose I have to ring the doctor, but only if Charlie wasn't here. (Mrs Osborne)

I'd ring my two sons, or probably belt on the walls to get Arthur (the neighbour), to help. I'd ring the ambulance if I'm real bad. (Mr Hatley)

Caregivers responded similarly:

(I'd call my daughter first. I always do if there is anything wrong with Dawn (my wife) that I can't deal with. If she (Dawn) needs help, or something's wrong, she always turns to me for help. (Mr Quinlan husband and caregiver of woman with advanced Alzheimer's disease)

Self-reliance and family support, minimising calls for formal assistance, were values that were further stressed in response to questions which concerned the course of action respondents would take if a pattern of longer-term need for help was identified.

I'm muchly against the Meals on Wheels and Home Care Type of thing. I would have to be really incapable and have no help, to call on community services. Whats the good of it anyway? Meals on Wheels is only five days a week. (Mrs Dawson)

I'd try and do it myself, even if I thought I couldn't. But if I had to I'd ask Charlie, because he's no trouble. He's always good hearted. (Mrs Osborne)

I'd prefer to do it myself. Community services I suppose are OK, (pause) but only if you really need it, really try a bit first. If you don't give it a go yourself ... I think you can call on them too early. (You've got to) learn to look after yourself and try a little bit. (Mr Quinlan, caregiver)

Sixteen of the participants, approximately 40 per cent of those that answered the question, initially said they would prefer to use community services rather than rely on caregivers or family. But even amongst those who indicated they would chose help from community services, the process of prior consultation with family seemed important.

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If I had to have help, I'd prefer community services. Yes. *Why would you choose this?* I hope I would never have to rely on Meals on Wheels, or that sort of thing, but it could happen. The family have already got enough to do themselves ... but if it was just occasionally, I would ask Neil (my son) or my family first. (Mrs Pope)

### **The Inquiry and Referral Stage**

The next step before assistance can be received consists of an inquiry and possible referral to a service providing agency. For services, referrals were therefore the first procedure in the service allocation process, and represent an essential and easily identifiable component of the allocation mechanism.

Records on the source of referrals were not available from all services. From those that did make their records available, it appears that most referrals came from other health agencies and general practitioners. Most coordinators emphasised that they welcomed self-referrals by clients. But amongst those who had referred themselves, advice provided by medical practitioners was frequently crucial. This was a point emphasised by participants in the study, who, virtually without exception, said that the general practitioner was the person to whom they would turn if they felt they needed advice about their need for help and the types of help available. Access to the service allocation process was thus weighted toward those potential consumers who could rely on a well informed GP, or who otherwise had contact with the service providers' network.

Two types of problems were identified with the system of referrals by service providers. First was the failure of many clients and caregivers to request advice or assistance when needed. Often, service providers claimed, this was because people were unaware of what was available. Without adequate information about the types of community support services available potential clients were likely to make what many coordinators considered to be 'uninformed choices'. In our discussions with service providers they were aware that many people in the community lacked this information.

In other instances it was clear that many potential clients were reluctant to ask for help. One of the reasons for this was they were, in the words of one coordinator, 'too independent' or 'too stubborn to admit they need help'. Although few would have described themselves in this way, a great many of the participants spoke with pride of their independence and ability to get by unaided, perhaps reflecting their social background as middle and working class Aussie battlers, discussed earlier in the report. As one of the women participants put it:

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You know you've got to stay, and you cope the best way you can. My father always taught us 'There's no such thing as can't.' ... You've just got to be determined and take each day as it comes.

Others may have held adverse preconceptions about the agency and were therefore reluctant to ask for help. Interestingly, many of the service staff pointed to the 'denial' they experienced when attempting to discuss the problems experienced by their clients.

A second type of problem identified concerned the regular failure of some medical practitioners, health professionals and other service providers to refer potential clients for assistance. In some cases, coordinators argued, this reflected a degree of ignorance or lack of information on behalf of the professionals involved. In other cases, staff were working under great pressure and preoccupied with activities in their department. But instances were also given in which the failure to refer was attributed to the professional's animosity towards community services.

Despite the difficulties encountered in attempting to gain access to services the referral of applicants continued, adding to the already full case loads all services were already experiencing. A number of strategies were applied by different services to manage the expressed demand and ensure that they were not overwhelmed or discredited in this process.

One approach was the subtle discouragement of referrals from other services. The coordinator of one service, with the equivalent of less than four full-time staff members, faced with the daunting task of responding to a continual stream of referrals, reported that:

We'd like to encourage other services to refer more but we're afraid of increasing the demand....We could not cope with more people. We couldn't possibly handle them all and would just have to put them on the waiting list.

When this had occurred in the past, she continued, the waiting list had grown to such lengths that mentioning it had discouraged other services from making all but the most serious referrals. To help cater for those people her service was not able to assist, advice was given about the use of private help and a list of names of those who gave pensioner discounts and had proven honest, reliable and economic in the past made available.

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### The Assessment Stage

The assessment procedure, which involves the documentation and evaluation of an applicant's needs by the service provider, comprised the next stage in the service allocation process. Although systematic and detailed information could have been readily obtained for many referrals, either from the Assessment Team, the general practitioner or from existing services, all but two of the eleven services consulted reported that they relied on their own personal in-home assessments to determine the needs of an applicant.

Determining need through an assessment, in this instance, means more than simply obtaining information about details such as the age of the client, their residential circumstances, their medical condition, ability to perform activities of daily living and the availability of informal care. The assessment was also concerned with matching the client to the sort of assistance the particular service can provide, and, in many cases, with obtaining information necessary for actually planning the work. As Healey has pointed out, assessment procedures perform many functions, ranging from screening for eligibility, determining the client's diagnosis and providing an opportunity for direct consultation between service staff and the applicant, to facilitating service planning and case review (Healey, 1993: 171). Thus the assessment procedure, in some respects, conflicts with the ideals of client choice. The importance placed on the professional assessment places the service provider in a position of exercising control, in some cases minimising the client's influence over the final results of the procedure.

When conducting an assessment, most service providers reported that they were not interested just in the applicant but in the caregiver, who was widely regarded as an important factor in determining a person's ability to remain at home and usually considered part of the client target group. The caregiver, according to the service providers, was therefore consulted as part of the assessment procedure. Both their needs, and their capacity to provide help had to be taken into account.

The procedures used to conduct an assessment varied somewhat from service to service, but most relied on a home visit which lasted anywhere from 30 to 90 minutes, providing an opportunity to meet the applicant and his or her caregiver, and collect sufficient information on which to make subsequent decisions. In the case of the Aged Care Assessment Team, described in Section 2, several visits by staff members with different areas of professional expertise might be required before an assessment could be considered to be complete.

In describing what was involved in conducting an assessment, the director of one of the Municipal Home Nursing services stated that:

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We look at each client individually and as a whole; that is (we also consider) the family support services available. We have to balance what they'd like and what they need. They are not always the same (so we) try and compromise and balance and suggest other things.

In the view of many service providers, applicants often know little more than that they think they need help at the time of referral. The home visit assessment was thus regarded as an opportunity for service personnel to clarify the situation, and, using their judgement, to determine precisely what it is that is the problem, at the same time exploring ways in which any assistance provided might be adjusted or arranged to suit the situation. Emphasising how applicants often did not know what their own needs were, another of the Home Nursing services described their assessment procedure as follows:

(Their needs are) not necessarily what they say they are. What they are telling you is not necessarily a fact. On a home visit we look at everything in their environment, as well as checking their medications and medical history.

The assessment was conducted, in most cases, by senior staff, often by one or two individuals who specialised in this. Typically, the assessment took the form of a home visit, often combining elements of an apparently informal chat with direct observations and the completion of paperwork. Service coordinators typically stressed the importance of observing clients in their own environment. This emphasis on learning about the applicant *in situ*, in their own home, as part of an already existing system of social support, was emphasised by a number of different service personnel. The Meals on Wheels coordinator, for example described the assessment procedure used by her service as consisting of:

home visits, conversation - ask what they need, check on shopping, see if they are coping. We observe, pick it up, check with family, neighbours and doctor.

Although much objective information needed to be obtained, the assessment procedure employed by most services was essentially subjective and discretionary, depending greatly on the experience of the assessor. Judgements about need were then made, often on the basis of professional knowledge, experience, 'gut feelings' and the feedback from subsequent visits. Few services followed strict guidelines or performed formal medical assessments that measured the client's ability to perform tasks of daily living and or cognitive functioning. The absence of these sorts of standard measures or procedures in turn meant that much of the information obtained could not be openly shared between organisations.

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The criteria used when determining need varied considerably between the different types of service concerned. For example the need for nursing services, it was reported, was determined as much as possible on the basis of medical necessity, with the assessing nurse combining information obtained from the client and caregiver(s) with that provided by the general practitioner and her own observations and judgement. Similarly, although they reported that in determining priorities for further assistance emphasis was placed on the potential to benefit from active therapeutic intervention, the Aged Care Assessment Team staff also emphasised the importance of medical criteria for determining the initial urgency of the intervention.

In contrast, Home Care staff followed an assessment protocol developed by head office. This combined the collection of demographic details about the applicant, the problems they were experiencing and their perceived needs for support, their household and care arrangements and an appraisal of their financial circumstances. Because much of the Home Care Service's work concerned household upkeep, part of the assessment was also reported to involve a thorough review of the home, with estimates being made for the time required to vacuum and sweep rooms clean, undertake dusting and so forth. Although some medical details are collected, it was stressed that the home care assessment is essentially an appraisal of the domestic circumstances and need for support and assistance and not a medical procedure. The Home Care services, although not the only agencies employing a means test, were also the only ones to specifically consider the financial situation of a client as an integral part of the assessment procedure.

Despite the absence of a common assessment protocol, most services did record information on a similar set of topics. These included the demographic details of the applicant and caregiver, a brief medical history and a record of the sorts of activities for which help was requested. The amount and type of assistance provided by the caregiver, if available, was also emphasised. The interpretation of this information for making decisions about the allocation of assistance to clients, however, differed considerably between services, an issue that is examined shortly.

Community Options coordinators stood out somewhat by insisting that they did not undertake an assessment at all. Instead, they said, they visited the applicant at home and conducted a 'conversation' with them, focusing on the things with which they said they needed help.

We ask about such matters as shopping, podiatry and transport. We'd ask about their problems and difficulties, and may prompt to get them to think if they have difficulties in an area. (We aim to) identify a problem and find options and appropriate solutions by discussing answers with them.

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Community Options coordinators were also the only ones not to carry a bundle of paperwork to be completed. While a large part of other assessment visits could be characterised as the agency staff getting answers to a set of predetermined questions, Community Options staff placed great store on conducting their assessments as 'conversations', with important information committed to memory and only later written down.

Two other agencies, the Day Care Centre and the Home Maintenance and Modification Service, stood out because they only conducted assessments over the telephone, relying on information provided by the general practitioner or referral agencies for further details. Otherwise, very few services reported that they ever relied on assessments conducted by other agencies. As most service providers performed their own assessments, clients could, in theory, be assessed and reassessed on a number of occasions. There were, however, no participants or caregivers involved in the study who reported problems with this matter.

The importance of performing their own assessments was stressed by the service providers as each service required different information. It was also clear that while assessments are spoken of as primarily being intended to benefit the client, they also served, as Healy (1993) in Australia and Ann Dill (1990) in the USA, have argued, to maintain the service's autonomy and control over its work flow.

There were considerable differences apparent among services in the degree of urgency with which referrals were treated. The managers of some services clearly prided themselves in making a quick response to any referral, treating a notification as a matter of urgency requiring immediate attention. Others, in contrast, reported that referrals were regarded as a simply part of a normal process of service provision, which should not, except in the most exceptional of circumstances, be given priority over already existing commitments. The Branch Managers of the Home Care Service were particularly insistent on this point.

Referrals were received not just from and on behalf of people in their own homes, but from hospital staff on the ward needing to discharge patients to free up hospital beds. Over recent years there have been a number of changes in hospital discharge procedures, of which the most significant, from their perspective, has been the reduction in length of stay in hospitals and the pressure this has placed on community support services to assist clients placed in the home with little or no preparation and follow up. The difficulty was that while they felt it necessary to respond to these referrals, as the people discharged required help to remain at home, providing assistance to patients with acute and post-acute problems decreased their capacity to provide assistance to existing longer term clients and other new referrals in their traditional client group.

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Sometimes a ploy of an administrative delay was deliberately used to deal with such problems. As the Director of one of the Home Nursing services ironically put it:

It is surprising how many urgent Friday afternoon problems seem to solve themselves over the week end.

### **The Allocation Stage**

Once the assessment was completed the applicant's 'need for assistance' was determined. Service provision thus proceeded to what we refer to as the allocation stage, in which decisions were made about whether the service agency was able to assist, and if so, how, and with what amounts and type of assistance.

According to coordinators, few community support services employed rigid criteria to decide exactly how much assistance a particular client could receive. Rather, the allocation of assistance between different individuals was usually decided in a fairly flexible manner, without recourse to strict eligibility criteria. Allocation depended on a number of variables, as the case studies considered in Section 8 illustrated. These included the need for help, as articulated by the client and redefined by the service provider, the resources of the service provider and the availability of informal help.

Most, although not all service providers reported that the presence of a caregiver was a major factor affecting decisions about the amount and type of assistance which could be allocated to a client. Coordinators from a number of services, including Community Options, Day Care, the Aged Care Assessment Team and one of the Municipal Home Nursing Services, reported that they gave priority to applicants with a caregiver. This was a recognition that caregivers and other family members carried out important work, often under very stressful conditions, and made a significant contribution to the viability of the client's continued life at home. Some of these coordinators in fact claimed that it was their custom to allow the amount and type of assistance provided to be determined by the carer, as it was their experience that caregivers, most commonly, would only allow service to provide a minimum amount.

At the other extreme, representatives of some services, including the Meals on Wheels service and the managers of the Home Care branches, stated that the presence of a carer usually meant that the individual was better off than people who lived alone, and was therefore a lower priority for service. If the caregiver was managing adequately, it was argued, there was often no need for extra assistance. Providing help could, in these circumstances, actually undermine longstanding family relationships. Further complicating the picture, staff of a number of other services argued that in some cases carers needed relief, but in others were

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irrelevant to the decision. Many caregivers, in their experience, were reluctant to relinquish responsibility to a stranger. Those that seriously made a case for help had already made up their mind and it was therefore necessary to give them priority.

Few services offered a measured, standard amount of assistance to all new clients. Those that did, such as Day Care, the Community Shopping Service and Meals on Wheels, provided assistance of a kind that was inherently standardised. Even in some of these cases, the assistance initially offered was often limited and could be re-adjusted later after further informal assessment. But in most instances a more flexible approach was taken.

When deciding the amount of assistance a client would receive, staff of the Aged Care Assessment Team, for example, pointed out that it was not just a matter of deciding in the abstract, how much help should be given. Constraints on resources allocated by services over which the Assessment Team had no direct control, as well as the preparedness of applicants to accept help under the conditions it is offered had to be taken into account. In real life, allocative decisions, they claimed:

must be what is possible to be provided and what the clients will accept.

Recognition of the factors which underlie the determination of an individual's need is an acknowledgment that need is determined not as professional judgement about the capacity of applicants to adapt to life at home with appropriate supports, but as discretionary decision negotiated between service staff and clients, made with an awareness of the limited supply of assistance from services and the readiness of clients to submit themselves to its acceptance.

In most cases allocation decisions were made by the service provider on the basis of information gained from observation and the client's answers to questions. The clients were consulted but if the perceived needs differed between the service provider and the client a compromise could be negotiated. Staff from one of the Home Nursing services, for example, told us that when determining the amount of service a client would receive:

A lot depends on our professional judgement ... we have to balance what they'd like and what they need, they are not always the same - (we) try to compromise and balance and suggest other things.

However even the service provider's capacity to exercise control over the service's resources was limited, a feature which is crucial to understanding the assessment

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process. The dilemmas faced were described by one of the home care coordinators as follows:

We have to try and gauge how long the field staff would need. It's a sort of combination of information given to us by clients, the field coordinators and the field staff. ... (We use our) initial judgement and rely on feedback from the field staff. It's basic maintenance only, we are not there to take over. ... Establishing priority is also very important, because we're working within a budget. If higher priority people come along, we take off the lower priority people.

Clients were able to influence the amount and type of assistance provided. It is clear, however, that the extent of their influence depended greatly on the degree of discretion available to service staff. Clients could, for example, request more assistance than the service provider initially had in mind, but there was no guarantee they would be able to receive it. Thus, although all services claimed to respect the client's right to choose, a range of different approaches were utilised which recognised the limited resources available and the necessity of working within these limits to assist as many clients as possible.

### **The Service Delivery Stage**

For most applicants the receipt of assistance, which represented the main goal of the process which started with an inquiry and referral, was achieved within a short time. If the problem required urgent attention, the entire process could be completed in an afternoon. The Home Nursing services took particular pride in this point. More commonly, however, several days were required, while in a few instances, two or more weeks could be involved. Having achieved their goal, little more was required of clients who were successful in obtaining assistance than that they learn to accommodate the schedules and operational routines of the different services, discussed in Section 10 of this report.

For some applicants the process ended here as well, with services continuing indefinitely. Increasingly, however, service receipt was becoming a temporary measure. To be able to continue to operate within the limits of their resources some services accepted clients only on a temporary basis.

The Meals on Wheels coordinator, for example, stated:

We are meeting demand which fluctuates, so you hold on through the pressured stages.

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Given the financial regime affecting her service and the constant shortage of volunteers to deliver meals, she was simply unable to provide assistance to all who made enquiries about it. She reported that she had learnt from experience to provide most clients with assistance on a temporary basis only, at least in the initial stages.

I usually set a limit for everyone. For example an ex-surgery patient would get one to six weeks which I would extend by three weeks if necessary if there is no improvement. I explain that I can't help everyone and need to help only when necessary.

This strategy, she remarked, had proved itself by reducing the numbers of clients who became long term, as it gave many clients the incentive and confidence to regain their self-sufficiency.

Others services developed different ways of adjusting to the same problem. One of the Home Care branch managers explained that clients were provided with assistance as long as it was possible, but when there was pressure on the branch it was sometimes necessary to go over budget for a period and wait for 'natural attrition' to compensate. Another manager explained:

We take low need/low priority people off service if necessary and give them information about alternative services.

Home Nursing services tended to have a wider range of clients, some with only a short-term need for help. Amongst those with long-term service clients were prioritised into high and low need.

People with (a need for) daily dressings, diabetics and palliative care are at the top of the list, showering are the lowest priority. We try to see everyone on the list, but if its not possible we cut off the showering.

Another element of service delivery was to keep the expectations of the client at a modest level.

When we start we contract with the client. Its best to start with a little and then add on (if its necessary). It is hard to withdraw services.

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### **11.3 The Service Provision Pathway and Other Strategies for Managing Resources**

The at times complex process through which new applicants proceeded in order to gain assistance from community services would appear to have been sufficient to ensure that the demands for formal assistance were minimised, and the services given every opportunity to operate within the limits set by their resource constraints. But despite the often complex procedures and the reluctance of many potential consumers to request help while they remained at home, service managers believed the demand for assistance still far outstripped the capacity of their services.

Virtually all community services staff mentioned, in this context, that in recent years there has been an increase in the level of demand for assistance which corresponded with reduced rates of entry into nursing homes and a continuing shortage of hostel beds in Broadleigh. The Community Shopping Service and the Home Maintenance and Modification Service, were, however, the only services with whom we spoke which maintained waiting lists. For most other services a number of other constraints operated, which, together with the allocation process outlined above, had the effect of enabling the supply of assistance to be brought into balance with the articulated demand.

#### **Managing Demand Before Referral**

Even before a potential client's need for assistance could be expressed as a referral, several factors limited the expression of demand. Those which lie outside the direct control of service personnel, such as the failure of medical professionals to refer, were the subject of quite pointed criticism by the coordinators with whom we spoke. Others, such as the reluctance of many older people to ask for help, were commented on with regret. But some strategies were used quite deliberately by service management as a means of limiting the demands made on their staff.

The absence of publicity was most often, perhaps, more a matter of fortuitous public neglect than a deliberate withholding of information by providers. Nonetheless, there was a clear reluctance on behalf of service management to remedy the situation by advertising or seeking publicity, as a number of different service coordinators made clear to us early in the study.

We haven't advertised this year. We don't dare ... not after our experience last year.

Quite frankly, we've got enough work without extra publicity.

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There's always a waiting list, so we don't need to advertise!  
Heaven forbid.

Even advertising for volunteers could bring difficulties. This became clear during the research with participants, when the daughter caregiver of one participant who lived on her own reported how she only learnt that a particular service existed when she saw it advertising for volunteers. An equivalent anecdote was given by the coordinator of the same service who related the rather humorous experience of being swamped with enquiries for assistance after gaining publicity from a local newspaper as a part of volunteer recruitment drive. She said,

I vowed then, never again! I advertised because I needed help,  
not more people who needed help.

As reported earlier, many service coordinators believed that the lack of information for potential participants about the community support services available was aggravated by the inadequacies of referrals from medical practitioners and other health professionals. It was probably not possible for a systematic publicity campaign to be developed to remedy this situation for a variety of reasons, not least of which were the limited finances and degree of fragmentation between services at the local level, and the inadequacy of the State administration of the HACC program at a broader level. But it does seem clear that had there been a much greater rate of referral to services from local medical practitioners, the result would have been likely to be similar to the problems experienced when publicity was given to the volunteer recruitment drive.

Some services had a policy of deliberately disregarding the financial circumstances of clients in order not to discriminate. But despite the reluctance of many older people to ask for help from charities, as Moen (1978) and others have documented, other services took steps which seemed to confirm their image of a welfare agency for the underprivileged, specifically targeting low income clients and referring on those with higher incomes. With an apparently similar motivation, the Home Care Service of New South Wales also introduced a statewide policy which gave priority to low income clients, referring most other applicants to private services. As the manager of one of the branches explained:

This is a welfare service - a government welfare service. It is  
not an entitlement. You need to be frail aged.

To emphasise her point, she continued, explaining that preference was now given to financially disadvantaged and low-income clients.

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### After Referral

When service providers found they were unable to meet the needs of new applicants, a number of other strategies were employed in the final stages of the allocation process.

Perhaps the most common was to divert the demand for assistance by refusing to accept responsibility for new referrals. Enquiries for forms of assistance which were not the clear responsibility of any particular agency, such as for physiotherapy or assistance with the care of dementia patients, were also frequently handled this way, with enquiries in many cases getting no further than the telephonist. Another common approach, often used when services were operating at full capacity, was to refer enquiries onwards to other agencies or back to the original source, without undertaking an assessment. Virtually every agency reported that they engaged in this practice, of necessity, as preliminary enquiries about possible referrals were often exploratory, simply seeking information, or were inappropriate, seeking a form of assistance that the particular agency could not provide. When this approach was used, it was usually without any record of a refusal being made, or, at best with a simple record of a telephone inquiry.

Another diversionary approach was to refer the applicant on to private contractors. This approach was used at the inquiry/referral stage, immediately following assessment, and in some instances even after assistance has been provided for a period. Most services regularly referred certain clients on to a variety of private service providers, including private housekeepers, gardeners and handymen, private medical and paramedical staff. The strategy had, however, been of particular importance for the Broadleigh branches of the Home Care Service of New South Wales which, in 1991 and 1992, in accordance with the new statewide policy of giving priority to clients with high needs, had needed to reduce the amount of staff time spent on routine house cleaning and gardening in order to increase the amount of intensive personal care provided. Elements of this process were described by one of the branch managers as follows:

We try to take low need/low priority people off service and give them information about alternative services. ... For example, we have just withdrawn 58 and a half hours lawn-mowing (every week). We have not been popular but I'm not here to win a popularity contest. We give people alternatives (which cost) \$20-35 an hour for lawn-mowing.

Having accepted a referral, and undertaken an assessment, in certain circumstances some services, rather than referring on or refusing assistance to new clients, would attempt to accommodate them by increasing the number of people they are seeing

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by decreasing the amount of time they spent with each client. As the director of one Home Nursing Service stated, this meant that:

No patient gets left out, but the amount of time with each patient decreases

Similarly, pressures had also been experienced by the Aged Care Assessment Team.

Our occasions of service have increased 13 per cent but referral rates increased 30 per cent. What this means is that more people are visited less frequently.

## 11.4 Allocation as a Targeting Strategy

Each of the allocation strategies employed by services represented attempts by coordinators and management bodies to safeguard what they believed was their organisation's operational effectiveness, given the conditions imposed by the system of funding and administration under which they operated. Two underlying approaches to resource management were evident, both of which involved a form of targeting. The first provided some assistance to as many people as possible, thereby bolstering client numbers (an extensive pattern of allocation). Ensuring that all clients with demonstrable needs received assistance, an attempt was made to maximise equity of allocation. This approach was most commonly encountered amongst services funded by block grants. The second approach involved the concentration of resources on clients considered to have the highest need (an intensive pattern of allocation). Recognising that there was only a limited number of clients who could be served, those with the highest needs were given priority, thereby maximising the efficiency of allocation. This was the approach required of the Community Options service, which utilised a system of service-linked-payments for a limited number of clients. A similar approach was also increasingly the preferred approach of the Home Care Service of New South Wales. This suggests that alongside the amount and mechanisms of funding, the policies of the State administration could be significant determinants of allocative decision making.

That both approaches should be pursued at once by different services in the same locality is a reflection of the lack of coordination between services and an index of the extent to which the organisations have attempted to deal with this dilemma on their own terms. For clients, the difficulties faced in establishing eligibility for assistance when eligibility so often remained discretionary and provisional, must, at times, have been daunting.

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Central to the strategies adopted by all services was that assistance to clients was offered in a passive rather than active manner. The term 'passive intervention' is used here to describe the broad strategy followed when a client does not assertively request assistance but initially refuses or appears reluctant to accept assistance. Under these circumstances, it was common for service providers to leave it to the client to 'choose', and for it to be their responsibility to contact the service provider if they change their mind. A nursing service reported that:

We have a card which we leave if a person does not want service.

However, it was obviously difficult for people who were reluctant to request help in the first instance to pursue it further. The use of a passive intervention strategy is also evident when clients give the impression they are coping and do not need assistance. As one of the members of the Aged Care Assessment Team, cited earlier in the study, commented:

If people give the impression that they do not need help, it is easy to justify not providing a service

The objectives of services and their organisational philosophies, such as the promotion of independence and respect for the independence of clients at home, together with the practical strategies of passive intervention, the acceptance and diversion of referrals, and the procedures used for assessing and prioritising the needs of applicants and providing assistance to particular clients, were ways of responding to the structural conditions encountered by the organisations providing community support services. They enabled service providers to operate with limited resources to meet the noble sounding but rather vaguely defined ideals associated with community support policies. These principles and practices inspired and motivated staff, at the same time as allowing the organisations to function within their operating constraints by stemming the flow of potential community support clients to a system with finite resources. Whilst embodying the objectives of community care policy they also appeared to contribute to the relatively low use of services by those who remained at home.

## 11.5 Summary

In summary, many factors have been identified which could contribute to the relatively low use of services amongst participants reported earlier in the study. At one level there were the potential clients and their caregivers, who often did not have adequate information about the type and level of services available. They were also frequently proudly independent and held quite strong opinions about what sort of help, if any, they required. Operating simultaneously, but on a

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different level, were the management and personnel of the service providing organisations responsible for extending assistance to those at home in need. While they could exercise somewhat more control in the process of decision making associated with the allocation of assistance, their options, too, were limited.

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# 12 Summary and Conclusion

The study of community support in Broadleigh set out to address four fundamental questions concerned with the longer-term implications of community support policies. In this final section of the report we reconsider the main conclusions of the study as they relate to these questions and reflect on some of the further questions the study has raised.

## 12.1 Research Questions

### **The Need for Support at Home and the Outcomes of its Receipt**

The study followed a group of 60 predominantly older people, the participants, referred to the Broadleigh Aged Care Assessment Team as a result of doubts about their capacity to continue to remain living at home as a result of disabilities and illness. As we followed them over a period of three years, it became clear that any link between their need for help and the outcomes of their attempts to remain at home was a complex one, making it difficult to predict the likelihood of any individual being successful.

All participants in the study required some form of regular help as a result of the disabilities. Virtually all participants needed help with transport and with shopping, and the overwhelming majority were also unable to undertake housework on their own. Over half the participants were also unable to cook for themselves. Fortunately, assistance with these activities can be planned on a regular basis and in most instances does not need to be provided on a daily basis. Those who were not able to rely on daily help from a co-resident caregiver were able to remain living at home, but unless they received regular assistance they tended to become cut off from the world outside, restricted to their place of residence and the activities they could undertake on their own there.

A smaller proportion of participants needed help with daily personal care activities such as bathing or showering, dressing, moving around at home, using the toilet or managing the ongoing problems associated with incontinence and each of those who was able to remain at home relied on assistance from a co-resident caregiver, usually their wife or husband. No participant remained at home who was bedbound for a prolonged period or who was unable to eat or communicate without help. Those with extreme levels of incapacity requiring round the clock supervision and care were admitted to nursing homes, in most instances shortly after the problems were first reported.

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Over the three year period of the study there was steady rate of admission of the participants to residential care. Twenty participants were admitted to nursing homes and two to hostels during the course of the study. After three years less than half remained at home. If the number who died while at home is added, it could be claimed that the home provided a viable form of accommodation and care for just over 60 per cent of all participants. For well over a third of the sample, however, support at home was not a viable long term alternative to residential care.

Despite the fact that people living alone generally had a lower level of need for assistance than those living with others, the rate of admission was particularly high for people living on their own. This suggests that the availability of co-residential help made a significant contribution to the ability of many of the participants to remain living at home. Despite the availability of assistance from community support services and other sources, those living alone were more vulnerable at home and faced an increased likelihood of being admitted to a nursing home or hostel.

The need for assistance at home was particularly marked for participants suffering from cognitive or behavioural problems, of which the most common form was dementia. The situation of those who were living alone was particularly precarious. Although the special need for additional ongoing care of those suffering cognitive or behavioural problems was not always apparent in the measures of disability recorded using the Activities of Daily Living (ADL) scale, other information collected during the course of the study and their higher rates of admission to nursing homes served to identify a need for ongoing supervision and companionship. The absence of this form of support was not compensated for by the intermittent assistance received from visiting service personnel or a caregiver living elsewhere. This was a telling feature in the almost complete inability of most participants with cognitive or behavioural problems living on their own to remain at home for more than a few months.

### **The Resources Provided to Assist Those Who Remain at Home**

The major form of support provided to support those who wished to remain at home were community support services. Participants were able to seek assistance from a wide range of specialised services that had been established in Broadleigh over a period of approximately 35 years. In total there were more than 16 different services providing domiciliary support of some kind to people in their own home, in addition to a further 15 specialised day care centres.

Although administered by five separate State Government departments and an independent statutory authority (the Home Care Service of new South Wales), the major funding source for the services was the Home and Community Care Program

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(HACC) introduced in the State in 1986. There were, however, a number of other sources of funding. Many domiciliary services continued to receive a substantial proportion of their budget from Municipal Councils, the NSW Department of Health and other government departments. A number of day centres received no assistance whatsoever from any government source. The system of funding and governmental administration, together with other organisational characteristics of the services in Broadleigh, made service provision a highly complex field.

The complexity of the system of service provisions may also have contributed to the relatively modest use made of services by participants in the study. The extent of service use is discussed in detail in Section 8 of the report. The contribution of community support services is also considered below as part of the response to the third research question.

### **The Relative Significance of Formal and Informal Sources of Support in the Home**

The availability of informal support emerged as the most important factor in the provision of support to almost all participants at home. It was particularly crucial for those who needed assistance with personal care. Although there were often several individuals who provided some form of physical or emotional support, most participants relied heavily on one or two people with whom they had a more intimate relationship who served as caregivers. Daughters and sons were most commonly the main caregivers of those living on their own, whilst spouses (both wives and husbands), and siblings were the most important concerned with providing care to those who lived with others. There were relatively few instances of caregiving by friends and neighbours, particularly amongst those participants who remained at home over the entire three years of the study, a feature which highlighted the vulnerability of participants who lacked primary familial bonds with those who provided support. There was also a number of people, approximately 20 per cent of the original sample, who could not identify a caregiver.

Reflecting the importance of informal care, participants without caregivers were, of necessity, more independent and less incapacitated than those with caregivers. Participants who lived on their own, even those whose caregivers visited frequently, in turn, needed less care than those who lived with others and were able to depend on the assistance provided by their co-resident. The study found that caregivers provided most of the non-technical help needed by those at home, particularly transport, shopping and, only to a slightly lesser extent, with housekeeping, cooking and personal care. At both the time of referral and three years later, caregivers provided personal care on either a daily or continual basis for approximately a third of the participants.

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The contribution of formal services in maintaining people at home proved more difficult to document. This may simply have reflected the relatively low levels of service use reported by most participants and caregivers. Alternatively, it may reflect the inadequacy of the research methodology for measuring the impact of service provision. To be more certain of any findings in this regard, comparison of a sample of participants in receipt of assistance from services with a matched a control group without such assistance would be required. Access to detailed official figures on service provision would also be necessary. There was some evidence from the study which showed that services such as home nursing and home care, even when received in small amounts for only a short period, had been crucial in helping individuals. In other cases, relatively small amounts of formal assistance appeared to contribute significantly to the quality of life enjoyed by participants.

A comparison of the contribution of formal and informal sources of assistance to the support of participants was provided in Section 8. This showed that in all activities except personal care, the proportion of participants assisted by caregivers far exceeded the proportion assisted by services. In the second year of the study, all assistance provided by services for shopping and cooking, and a high proportion of the assistance provided by services for personal care activities such as bathing and dressing, actually went to participants with physical problems living on their own, who did not have a co-residential caregiver to assist them. Some assistance was also provided with personal care to high dependency participants living with others. This increased in significance over the duration of the study as their need for care increased and as participants living alone were admitted to residential care. The contribution of services was more marked with regard to housekeeping. In other activities, such as shopping and cooking which, because of their intermittent nature, do not require intensive intervention, the proportion of people assisted by services was considerably lower, with most participants relying on assistance provided by informal caregivers. This suggests that service delivery emphasising personal care was targeted at those who live alone and those with very high levels of dependency, while other activities which could be managed more successfully by a non-resident caregiver were being undertaken predominantly by informal caregivers.

### **The Relationship Between Community Support and Other Provisions**

Community support is often regarded as an alternative to residential care. Rather than providing an alternative, however, in Broadleigh it appears to have been an adjunct, with the relatively plentiful supply of nursing home facilities in the locality acting as a form of social safety valve for those whose life at home was being placed under pressure. The figures on admissions to residential care presented in

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this report show that for around 40 per cent of the cohort, community support did not provide an enduring viable alternative to residential care. Remaining at home, it could be argued, did provide participants with some degree of choice which they might not otherwise have enjoyed. It also enabled them to postpone admission. For some this was merely postponing the inevitable, and their extra time at home lasted only a matter of weeks. For others, however, the measures provided them with extra months and even years at home. For each of these people, reliance on support at home and then later in nursing home care, demonstrated that the two forms of support supplemented rather than substituted for each other. Each assisted participants with different needs and access to support, at different stages of their history of support.

As discussed in Section 3, however, it was not possible to determine whether community care was an alternative, in any sense, to nursing homes for all participants, as their eligibility for nursing home admission was not tested in a strict sense at the time of their referral to the Broadleigh Assessment Team. Although prescriptive guidelines operate stipulating the minimum level of care required for admission, nursing home eligibility is, to an extent a question of negotiation between authorised assessment staff and clients and their caregivers. Many of the participants, had they requested it, would probably have been assessed as eligible, but for a considerable proportion of those included in the cohort, it is doubtful whether this would have been the case. Community support may have been an alternative to admission to a hostel for those who maintained a degree of independent mobility and who remained capable of assisting themselves in matters of household help and personal care. But equally, it was also likely that many participants would have chosen to remain at home whatever the options. The expansion of community service provisions through the HACC program enabled many of these people to receive a degree of support that they might not otherwise have enjoyed, enhancing their quality of life at home and, in some cases, facilitating their continuing participation in community activities and social relationships outside the home.

## **12.2 Compensation, Complementarity or Neglect?**

Unfortunately, the findings concerning the apparent imbalance between formal and informal support evident in these results do not permit us to reach any firm conclusions about the essential character of community support in Broadleigh and the relative contributions made by formal, publicly funded services, and informal, familial caregivers. But the fundamental questions raised by conservatives, feminists and some radical critics of community care outlined in Section 1 of this report should still be posed: Is there evidence of the displacement by public agencies of the caring support that families would otherwise provide? Does the

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evidence suggest instead that community support is an approach which results in a form of public neglect, leaving the work to informal caregivers (amongst whom are a majority of women) whenever possible? Or is the assistance provided by services essentially compensating for shortcomings in family-based caregiving, or playing a complementary role to it?

The first question, which arises largely in the context of conservative debates about the role of government, has been most clearly articulated in the United States, where successful arguments against the expansion of community support programs have been raised on both moral and financial grounds. One congressman, for example, was reported as claiming that increased expenditure on community and social services for seniors would lead a 'shirking of family responsibilities' and not longer run cost reductions (Biaggi, cited in Chappell, 1992: 55). Confirming the results of numerous overseas studies (Chappell and Blandford, 1991; Chappell, 1992), we found no evidence of such a phenomenon. Quite the contrary! The extent of familial responsibility for supporting aged relatives documented was very significant and showed no sign of being displaced by government funded community services.

Perhaps more relevant, in the Australian context, is the second question, which suggests that low levels of service receipt by those at home are the result of a policy which, either deliberately or inadvertently, has shifted many of the costs of care from government to the family. Here the evidence is more equivocal. Certainly it appears from this study that the bulk of support for those at home was provided by unpaid caregivers. It could also be argued that community services, themselves poorly funded and staffed predominantly by women on low rates of pay, have played only a limited role in the support of participants at home. But against this must be placed the evidence of the relatively large number of people admitted to Commonwealth Government funded nursing homes and hostels, which surely do not represent a cost saving to the state. Further, a considerable number of participants and caregivers stated a preference for assistance to be provided by caregivers where possible, and for services to fill in where necessary. There were also numerous instances in the study in which participants simply refused the assistance available from services, just as in a great many of the cases encountered, the support provided by caregivers was a spontaneous and reciprocal gesture, which held the promise of mutual rewards for the recipient and the provider of care.<sup>40</sup>

This suggests that the third question, whether services were essentially compensating for shortcomings in family based caregiving, or playing a complementary role to it, may also be pertinent. In what many regard as a response

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<sup>40</sup> Clifford has recently argued more forcefully that this was commonly the case among caregivers in his study in the Irish Republic (Clifford, 1992).



to the criticism of American conservatives, Litwak (1985, see also Kendig, 1986) has argued that formal services, as bureaucratic organisations, are different from, and complementary to, families. Each is best suited to performing different types of tasks, the family providing emotional and non-technical support, while services are best at discreet and technical tasks. Much of the evidence from this study could be interpreted as confirming this approach. But the division of responsibility between informal caregivers and services, on close scrutiny, did not appear to conform entirely with the prescription offered by Litwak. Much of the assistance provided by services, for example, was of a non-technical kind. Further, the approach leaves little room for the preferences expressed by participants and caregivers, or for the shortcomings of service provision.

In this context, the 'hierarchical compensation' approach, advocated by Marjorie Cantor (1989, Cantor and Little 1985) appears to have significant explanatory capacity. She argues that a 'normative preference' exists for assistance from family members, with a hierarchy of preference existing in which help from a spouse is preferred to help from a child, that from a daughter to that from a son, and so on, with help from formal services being the least preferred, but still acceptable option for those seeking support to remain at home. The shared values between clients and staff of formal services enable service staff to mesh in with family care, each compensating for the other's deficiencies. The critique of this position by Finch and Mason (1990), which sees the issue as one of a negotiable process of normative choice, rather than undermining this position, appears to extend its explanatory value.

The home appeared in many ways to have been regarded as a private domain by both participants and service providers. It was also widely expected that when possible, those who needed assistance would seek this from their family members. Where these fell short, for whatever reason, it was considered appropriate to turn to formal services for assistance. In some cases, such as some Meals on Wheels services, guidelines existed which prevented assistance being provided to participants who lived within walking distance of family members. In other cases, priority was given to applicants without access to informal support in the home. Often the judgement remained unwritten and implicit, although no less operative than when expressed in written guidelines. For example, when asked about providing assistance to clients living with others, the manager of one of the largest community services in Broadleigh responded reflectively:

If existing family support is evident, sometimes its prudent not to take over service provision.

As well as providing participants with company and ongoing supervision or monitoring, caregivers were likely to undertake a wide variety of tasks, often at

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irregular intervals and times. It was evident that the division of household labour along lines of gender, with women most frequently taking special responsibility for caring and home making work, had a particular impact at this level. The majority of personal care and household work was undertaken by women, reflecting the situation in other households across Australia (Bittman, 1991). However, although women were clearly predominant, almost one in three caregivers in the first months were male, their proportion actually increasing over the three years. The informal work of caregiving appears to have been treated largely as home making, performed most commonly by women, but also, when necessary, by men. Where ongoing assistance was required, a co-residential caregiver, usually the spouse or sibling of the participant, appeared to be the most reliable and acceptable source of assistance. When assistance from a co-residential caregiver was not available daughters were the most likely providers of care. There were, in fact, more daughters providing assistance than caregivers in any other relationship. Where there was an option of either a son or daughter providing assistance, it appears in most cases that it has been a daughter who has taken on the greater level of responsibility. Often, however, neither spouse, co-residential sibling nor daughter was available. In these circumstances a son, in some but not all cases closely assisted by a daughter-in-law, was frequently the one who had taken on the responsibility of caregiving.

This pattern of social relations and preferences can be understood as expressing a system of cultural or moral values shared to an extent by participants, caregivers and services alike. It bears many of the hallmarks of what Finch and Mason refer to as the normative social consensus within which familial relationships are imbued with a sense of obligation, albeit one in which responsibility is open to a degree of negotiation (Finch and Mason, 1990). The ordering of preferences extends beyond the confines of the household and informal support network to encompass assistance provided by formal services, the widespread but restricted use of services showing them to be acceptable when necessary, although not, in most instances, the preferred source of assistance in the home. Confirming elements of Cantor's propositions and those of Finch and Mason, the relationship between formal and informal assistance evident from the study thus resembles a hierarchy of preferences, with formal assistance compensating, as it were, for inadequacies of informal support in some instances, supporting and reinforcing it in others.

What is perhaps less explicit in the model they propose is the preparedness of participants to accept admission to residential care, while ignoring the potential option of additional assistance from community services which would enable them to remain at home. Emphasising their ability to cope at home with minimal assistance from formal services, participants often only expressed requests for intensive assistance when there was little alternative but to seek admission to nursing homes. In this respect it was interesting to note the contrast in the relative

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preparedness of participants and their caregivers to make use of other types of formal advice and assistance, such as that provided by their general practitioner, medical specialists and hospitals. Their relationship with their doctor, for example, was often described in highly personal terms, as one which they had built up over the years. Seeking medical help was also a relatively familiar and often routine process. Further, help sought from the doctor was predicated on concepts of illness and cure rather than on the objective of preventing unnecessary institutionalisation which underlies the provision of domiciliary support services provided under the HACC program. Community services, in contrast, remained largely unfamiliar with the conditions of their provision often resembling that of charity. Accepting residential care as an alternative to family support also appeared to reflect a recognition of past and present patterns of provision, and was quite possibly also a rational and calculated judgement when the available alternatives were considered. It was also clear that the explicit objective of most of the formal services has been to supplement, rather than substitute for, assistance provided in nursing homes.

### **12.3 Towards the Interweaving of Formal and Informal Support**

The evidence from interviews with service providers in Broadleigh, cited in Sections 9 and 10, illustrates how resource constraints and client preferences, as well as culturally normative and professional values, influenced decisions about the allocation of assistance to clients. It was also shown that the services were provided to clients with specific and demonstrable needs for assistance. The assistance made available, it appears, was well targeted but limited by the means available. Consequently, while most participants who required and requested assistance from formal services were able to receive help, they received it in relatively small amounts, often insufficient to enable them to remain at home.

Achieving the ideal of a true 'interweaving' of formal and informal support (Twigg, 1993) is likely to require both more resources than have been available up to the present, and to require some changes in the organisation and funding of services. The current pattern of service provision is in part a legacy of previous policy initiatives. Despite the introduction of the HACC program which encompasses all services, differences between services are often pronounced because there has not been a unified approach to the development of community care at the State or local level which could counteract the ad hoc approach to planning and developing services, the absence of licensing or accreditation provisions, and the largely autonomous way in which each of the services functions. Nevertheless, a great many similarities remain between the operation of the different services which is evident in their mode of operation and in the unspoken agreement of the different services not to duplicate each other's activities or to extend into the territory of

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others. This pattern of similarities and differences is also manifest in their referral, assessment and allocation processes.

The organisational structure of individual services, and the articulation of this pattern of locally based organisation with the statewide administrative system of the HACC program appear to be important features underlying the development of both these differences and similarities. Their origin, like most other organisations encountered in the field of community support in NSW, is as local initiatives which, through time, have both responded to, and been incorporated in, national programs of service provision. Despite talk of needs based planning and service provision benchmarks (Fine, Graham and Webb, 1991), funding still appears to be provided very much within this framework, based in part on the timeliness of submissions for assistance, and in part by who, or which division of government it is, that is responsible for administering the funding. If they are to respond effectively to the increased and more complex demands made on them as the effective level of provision of nursing homes continues to be reduced, governments and services must be able to look towards a new organisational and funding regime.

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