Chapter 3
Results

The household survey

As discussed in the previous chapter, there were 2,058 household responses, representing 4,284 household members. Of these, 1,654 households had 2,599 members aged 50 years and over and the following results primarily reflect the responses of that group. These are compared with the results of the *New South Wales Older People's Health Survey 1999* (NSW Health 2000) and the literature specific to the issue under discussion.

Income

Of the 2,058 respondents, 1,465 were aged 50 years and over and of these, 883 or 42.3% had an income under $19,999, 443 or 21.5% had an income of $20,000 to $50,000, and 139 or 6.75% had an income in excess of $50,000. In the *New South Wales Older People's Health Survey 1999* (NSW Health 2000) '53.3% of older people said that they were financially comfortable, 43.7% said they had just enough to get along and 2.1% said they could not make ends meet' (see Figure 3.1).

The source of income for the respondents showed that 47% were in receipt of the pension and mostly the aged pension, 65% received the disability pension, 13% were self-funded retirees while 20.4% were employees and 17.9% were self employed. In the *New South Wales Older People's Health Survey 1999* (NSW Health 2000) 82% of older people reported receiving a pension or benefit.

While it would be expected that those in receipt of a pension and self-funded retirees would be in the 50 years and over age group, it was notable that 189 of the 409 employed were in the 50+ age group and 242 of the 359 self employed were similarly of that age group. In the *New South Wales Older People's Health Survey 1999* (NSW Health 2000) 6% indicated they were employed.

Housing

Of the respondents who answered this question, 1,711 of the 1,977 owned or were buying their own home, with 1,409 of this group of home owners being aged 50 years and over. For both the total sample and those aged 50+, home ownership was more than 80%. This indicates that the majority of respondents are asset rich while having a low disposable income. However, because of the

home ownership, the expenditure of household income is likely to be more discretionary than for those on higher incomes with mortgages and a greater number of dependants (NSW Department of Ageing & Disability 2000) (see Figure 3.2).

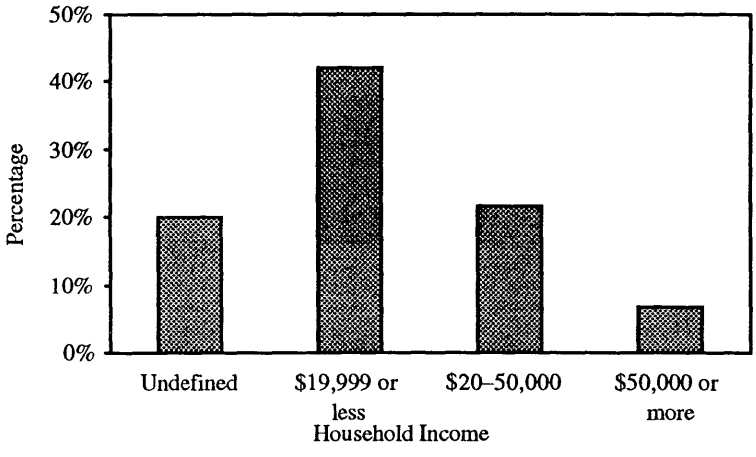

Figure 3.1: Household income

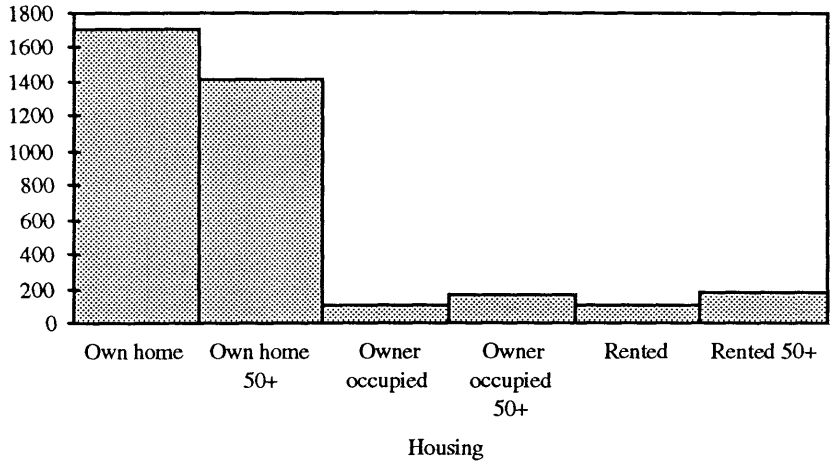

Figure 3.2: Home ownership of respondents over 50 years of age compared to total respondents

In the *New South Wales Older People's Health Survey 1999* (NSW Health 2000), 82% of older people reported owning their own home, 4.5% paid rent for public housing, 4.4% paid rent for private housing, 3.6% were leasing or purchasing in a retirement village, 2.7% were living rent or board free and 2% were paying off their own home.

Disability

The respondents reported 784 household members with a disability and, of these, 82.5% were aged 50 years and over (see Figure 3.3). Of the total reported

disability, 76% reported a physical disability, 13.8% an intellectual disability, 3.5% an intellectual and physical disability and 6.1% other disabilities (see Figure 3.4). Of this group 766 reported on the extent of disability with 48.4% reporting a medium disability, 28.5% a mild disability, and 22.9% a high disability. It is important to remember that the terms 'handicap' and 'disability' were not distinguished in the survey and would have been used interchangeably and no definitions were provided or applied to the extent of disability. The significant increase in physical disability amongst the 50 years and over age groups is illustrated in Figure 3.4.

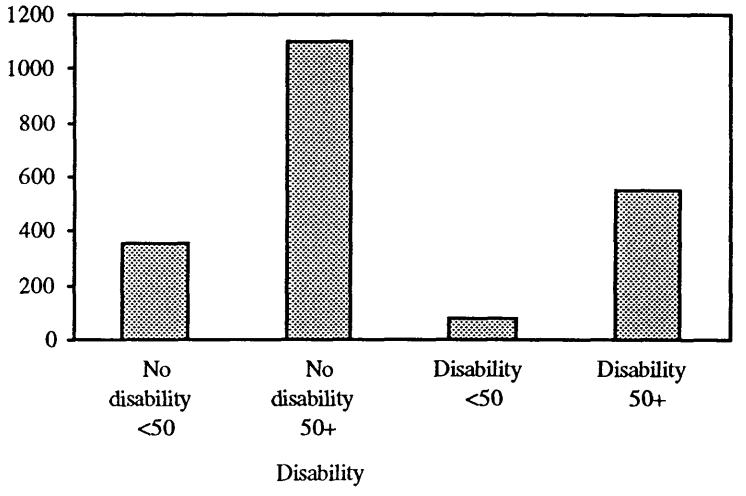

Figure 3.3 Household disability

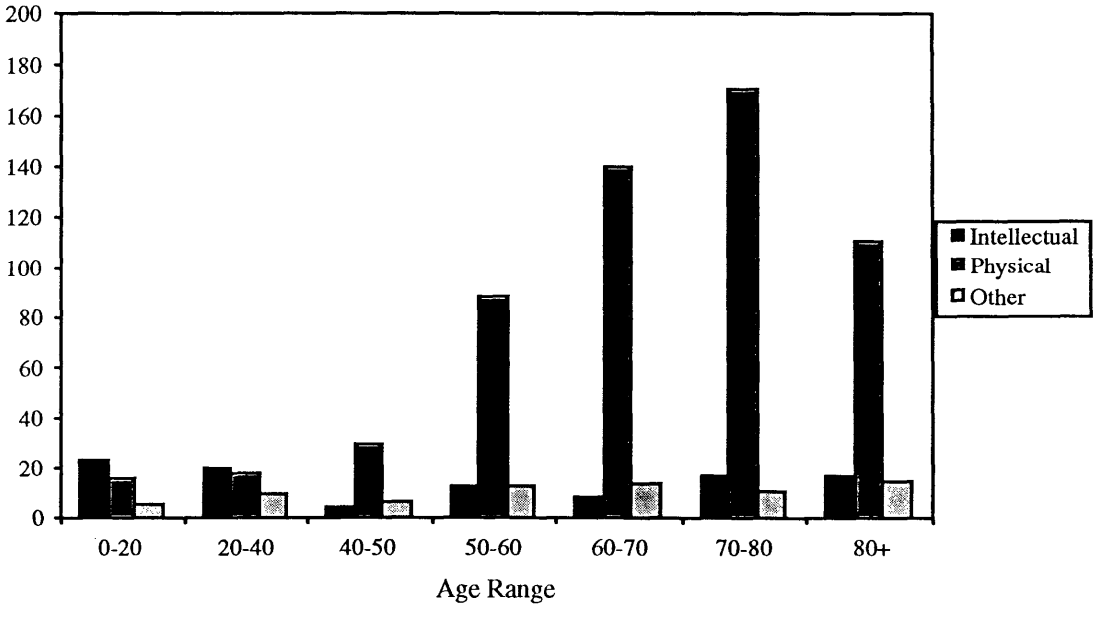

Figure 3.4 Disability type by age range

The *New South Wales Older People's Survey 1999* (NSW Health 2000) did not

directly attempt to measure disability or handicap. However, over one-third rated their health as 'very good' or 'excellent' and over 54% as 'fair' or 'poor'. Over one-third of older people said they have health problems that cause them difficulty in getting around and doing things for themselves. In terms of physical activity, 48.9% reported taking adequate physical activity and the most common reason for not being more physically active was health problems, while a small proportion (4.4%) identified problems with pain as a factor.

Care providers

In answer to the question as to who provides care to the aged/disabled members of the household, 1,367 or 66% responded. Of these 36% indicated that they cared for themselves, followed by 22% who indicated the family as the main carers group. In descending order, following the family as carers were Home Care, community health, HACC and friends, neighbour, hospital, Challenge Disability (service provider) and Department of Community Services.

The *New South Wales Older People's Survey 1999* (NSW Health 2000) found that 'almost one in 10 (9.2%) of older people indicated that they had the main responsibility in caring for someone who has a long-term illness, disability or other problem'.

Collopy, Dubler and Zuckerman (1990) found in the United States that:

> only a small percentage of the elderly in home care rely exclusively on paid or "formal" caregivers. In fact, families bear the primary burden of home care providing 80 percent of all days of home care in the United States (Special Committee on Aging 1987). Professional, formal home care generally functions to supplement or complement rather than replace family and other informal care. The national profile of family caregiving indicates that adult children are most frequently the primary caregivers, followed by spouses, siblings, and other relatives. Most of these caregivers are women and most caregivers have been providing assistance for one to four years, with 20 percent doing so for five years or more. Many of the caregivers are themselves elderly (35% over age 65), and approximately one-third of the caregivers work outside the home. About 80 percent provide assistance seven days, with spouses spending the largest amount of daily time on caregiving (Stone, Cafferata & Sangl 1987).

A British study by Vetter, Lewis and Llewellyn (1992) demonstrates that family members are the main care providers and describes the complex nature of the relationship between dependent elderly people living at home and their carers. It supports the existing view that one person, usually a daughter or spouse, makes a major contribution to caring. It also shows that the publicly provided services are

often involved with caring for highly dependent elderly people. It also indicates that this complexity has also led to an underestimate of the contribution of service providers. It suggests that 'these services can be further developed to alleviate the problems of those caring for elderly people at home'.

An American study by Boaz and Muller (1994) focuses on 'the different combinations of family helpers and living arrangements as indicators of different amounts of community help'. It shows the importance of family ties in reducing the risk of long-term nursing stays. It shows that 'when a spouse and children join forces as caregivers they reduce the risk of permanent residence in a nursing home more than any other combination of family helpers'. It suggests that 'the magnitude of the effects of family helpers and living arrangements lends support to the hypothesis that, when help is available at home, the risk of permanent nursing home residence is reduced'. Preferences of elders about who provides care depends on a number of variables and preferences cannot assume to be consistent for different types and durations of care or service provision (Wielink, Huijsman & McDonnell 1997:174).

Health and community service use

Of the 2,058 households surveyed, 855 or 41.5% indicated use of a range of health and community services representing 1,378 service uses. The overwhelming majority of this service use was visits to general practitioners, accounting for 40% of the total. Importantly, 78% of the general practitioner visits occurred monthly.

This dominant use of the local doctor was reinforced by the fact that it was far in excess of hospital, community health services and day care usage which together accounted for 13.5%. In fact, individually home care, home maintenance, shopping and transport had higher utilisation than the health services and were ranked in the order above, following in frequency the use of general practitioners.

The fact that nearly 50% did not use or report the use of services confirms a relatively well and independent group. Of the 855 respondents who used services, 731 or 85.5% were aged 50 years and over. Of the 584 who responded, 191 received free services, 206 obtained services from private contractors/firms, 115 from Home Care, 93 from a hospital, 25 from voluntary sources and 66 from other sources.

In the *New South Wales Older People's Health Survey 1999* (NSW Health,

2000:6):

> almost all the people surveyed had visited a general practitioner in the last 12 months and over one third had visited a general practitioner in the last two weeks. A small proportion reported a community nurse visit in the last 12 months (6.8%) or two weeks (2.7%).

In addition, 'one in five older people reported receiving help in the previous week from an organised community service for household duties, home maintenance or personal care'. This help was most commonly in the form of home maintenance, gardening, household duties and meals, in that descending order. 'About one in 12 people indicated that they needed help or more help with household duties, personal care, or other tasks at home. Again the most common need was for assistance with household duties and home maintenance or gardening.'

Newbury et al. (2000) report that 'general practitioners in Australia have recently been funded for "75+ health assessments"'. They concluded a randomised controlled trial of these assessments demonstrated that while physical functioning did not change, fewer people reported falls, fewer died and psychosocial functioning improved. Their study is 'consistent with the other published trials, showing modest improvement in the measured outcomes in the group aged 75 or over'. This change in the Medicare arrangements to allow screening of 75+ people by general practitioners occurred subsequent to the household survey.

Cates (1993) reports on reductions in institutionalisation of elderly people in Sweden and Denmark. A reduction of 23% in nursing home care in Denmark from 1980–89 and 34% overall institutionalisation in Sweden from 1970–1985 was reported. This was accomplished by increasing home care and housing with services and adaptations. In Sweden, he indicates that 'a reduction in demand for beds in a long-term care hospital has been achieved through a tightly coordinated system of care and services among the various health and social service professionals' (Cates 1993:271).

Challis, Darton, Johnson, Stone and Traske (1991) propose the use of case managers in multi-disciplinary geriatric teams to provide care packages and to deploy home help staff. In Oregon, USA, and in Sweden, a full range of health, personal care and domestic services is provided in association with assisted living facilities (Concannon 1995; Asplund & Bonita 1994).

Retirement and aged care housing preferences

A total of 1895 respondents indicated their retirement intentions, with 59% having already retired. One or two respondents indicated that they never envisaged retirement because they were full time carers of children with disabilities. In respect to the location of retirement, there was a very strong preference to retire locally, 77% of respondents, with only 10.9% indicating an intention to move outside the New England region on retirement. Again, of 1,787 respondents, 1,522 or 85% indicated that they would retire into their own home, 8% opting for rented housing, 4% for units/townhouses and just under 4% opting for retirement village housing.

In terms of more age care specific services and housing, there were 2,295 responses, with some respondents entering multiple choices. However, the majority, 51.8%, wanted to remain in their own homes and be provided with community services. The next choice was self-care units at 26.5%, followed by 9.4% who selected nursing home accommodation, then decreasing preferences for group homes, followed by hostels. In this context also, more than 48% of respondents indicated their willingness to contribute financially to these housing choices, 26% would invest to occupy while 28% would purchase, 8% would become investors, 9% would be prepared to contribute in some way, while 28% would rent or lease.

In the *New South Wales Older People's Health Survey 1999* (NSW Health 2000:12), '82% of people reported owning their own home', the rest rented, lived board-free, leased/purchased in a retirement village or were purchasing their own home. Over one-third of older people lived alone, three-quarters of older people lived in a separate house and the majority were married or living with a partner.

The responses to the study survey clearly demonstrate that when care is required there is a preference that it be received directly in the individual's own home, with a second preference for self-care units ahead of nursing homes. It is interesting to note that this latter preference also rated higher than hostel accommodation. The preference for home care ahead of other forms of accommodation is supported by other research. Hafez (1994) indicates that:

> surveys carried out in the countries of the Eastern Mediterranean region have confirmed that most people consider the home to be the place where the elderly should live and where they are likely to derive the greatest emotional satisfaction.

Asplund and Bonita (1994:28) state that:

> up to 40% of people over the age of 80 in Sweden either have some sort of home care or are cared for in facilities provided by each local council. The municipal councils also have responsibility for group homes, which in turn are based on a social model where personal autonomy is regarded as an important ingredient.

Concannon (1995:10) reports that in Oregon, USA:

> the home and community based care waiver allowed the state to use federal Medicaid funds previously earmarked for nursing home care for home and community based care. Proponents explained that the elderly were entitled to the same independence, dignity and quality of life enjoyed by the rest of Oregon's citizenry and wrote social policy for long-term, community-based care of the elderly squarely into statute.

This article further states that:

> the State of Oregon finds that the needs of the elderly population can best be served and planned for at the community level ... [and] that the elderly citizens of Oregon will receive the necessary care and services at the least cost and in the least confining situation ... Consequently, the proportion of private payers who choose nursing-home care has dropped from 60 percent to 40 percent, and the number of Medicaid-eligible nursing-facility residents has dropped from 8,400 to 7,200.

This same study confirmed that:

> during the 10 years prior to 1992, Oregon's over-65 population grew by more than 27 percent, according to a Portland State University report by Elizabeth A. Kutza. During the same period, the number of nursing-home beds per 1,000 population declined by 25 percent in Oregon. Oregon has 27 beds per 1,000 seniors, compared with 42 nationally. In absolute numbers, Oregon nursing facilities fell from 193 to 177.

Maher and Nolan (2000:52), in commenting on the needs of the aged and the limited ability to meet their needs in rural areas, introduce the concept of assisted living. They suggest that:

> to meet the needs of this burgeoning senior population, it is crucial to create more cost-effective and less restrictive alternatives to nursing home care, particularly for the Medicaid population. To date, the assisted living industry has created a substantial number of units for market-rate seniors (those with incomes in excess of $25,000 per year). Coming Home is focused on moving this industry to create those same options for low income seniors who outnumber market-rate seniors two to one. The philosophy of assisted living is to provide seniors with choice, autonomy, privacy, independence, dignity, and

> respect. These basic elements of life are no less important to those seniors of modest means.

The Coming Home program is an initiative of the Robert Wood Johnson Foundation (1994) in the USA, designed to help rural communities develop the capacity to meet the needs of residents who are elderly or chronically ill. It provides integrated systems of community-based care that link health and social services with independent and assisted-living housing options.

The Social Policy of the Foundation (1994) states that:

> The Coming Home program is intended to explore three models:
> - Expanding community health centres to provide a spectrum of long-term care services.
> - Converting or reconfiguring hospital services into a long-term care campus.
> - Using a consortium of rural health, housing, and social service providers to develop a continuum of long-term care services. These models will be appropriate in rural communities where growth or stability allows for an expansion of services or where a declining population necessitates the downsizing or reconfiguration of acute care services.

There are a variety of similar solutions across the world that are attempting to respond to the findings of this study and other research which highlights both the desire of the elderly and the desirability of social policy emphasising alternatives to institutional care. These include Oregon's Department of Senior and Disabled Services (DSDS), which manages all state and federally funded programs for long-term care and has a goal to make nursing home placement the last resort rather than the first choice.

Other solutions include the 'Friends House' in a suburban setting in Santa Rosa, California, established by a Quaker group and the On Lok program in San Francisco's Chinatown (Roberts 1991). The concept of 'boarding out' used in Ireland (O'Shea & Costello 1991), adult foster care in Oregon USA (Concannon 1995) and in Sweden the 'Service House' model of self contained apartments with a range of provided services, are further examples (Asplund & Bonita 1994). In contrast, Coll (1993) proposes that hospitals will acquire their own nursing homes and develop a range of residential options including day hospitals, 'swing beds', step down units and special care units. Again, all of these models reflect proposed policy directions under development in Australia as discussed in chapter one.

Notwithstanding this concentration on physical facilities, researchers and service

providers are also exploring the potential use of existing and emerging technology to both deliver services and to maintain individuals' independence and autonomy in residential lifestyle choices.

USA Today (2000:6) comments on the *21st Century Eldercare Trends Report* created by SCAN, a managed care plan for seniors that suggests that technology could be central to solving many of the health care challenges facing the country in the next 50 years. The report suggests that we will see:

> technology playing a major role in a reformed health care system, as "cyberseniors" are aided by personal computers to prolong independent living. Elder-friendly technology will significantly improve access to resources and information to assist those who are frail and vulnerable and will help to reduce isolation among those living in rural or hard-to-reach areas of the country. The increased use of personal computers will be a key factor in helping cyberseniors to remain living independently, as it will enhance their ability to communicate and obtain valuable health care information, Ervin emphasizes. Technology will also allow health care providers to better monitor their patients.

An article in *Business Week* (2000) reports on progress in Japan where personal sensors are in use to remotely monitor and record the movements of an elderly person living independently. Technology is incorporated in a household design to automatically operate appliances and services. A wet call wireless diaper system is in place to notify when an adult diaper requires changing. A power supply company has also established a home visiting personal/domestic care service to the users of its power supply. Lindberg (1997) reports on an interactive home health care program being trialled in rural Kansas to provide health care to the elderly and disabled using local cable systems and modified television. Personal safety and monitoring systems are increasingly used in aged care residential facilities. The potential for this technology to be used in the general community and to develop a 'virtual' aged care service is yet to be fully explored.

Responsibility for aged care services

This question was broad, with about 14 possible answers to tick, including a mix of service providers and funders. Many made multiple responses with the choices in descending order of importance and, as displayed in Figure 3.5, the percentage of total response is as follows:

Commonwealth government	71%
State government	66%
Community health	46%

Local hospital	37%
Local government	32%
Not-for-profit provider	25%
Churches	20%
Private aged care	18%
Salvation Army	13%
St Vincent de Paul	12%
Challenge Foundation	11%

Not only did respondents make multiple choices, but also a number of the categories are interchangeable. These results indicate a willingness to accept a wide range of providers but also clearly signal that the community believes all levels of government have a significant responsibility to provide aged care, directly or indirectly. The difference in views expressed in Figure 3.5 between those under 50 years and those over 50 years is also interesting. There appears to be a willingness to accept a larger group with more equal responsibility for aged care by those under 50 than those over 50. The preferences of the older group are more closely restricted to Commonwealth and State governments and health service providers of the State government.

Given that the State government also provides community health and hospital services, there is a clear message that the community was not persuaded by the debate just prior to the survey where New England Health Service denied responsibility for aged care residential services in small hospitals and where the arguments about commonwealth/state responsibility featured strongly.

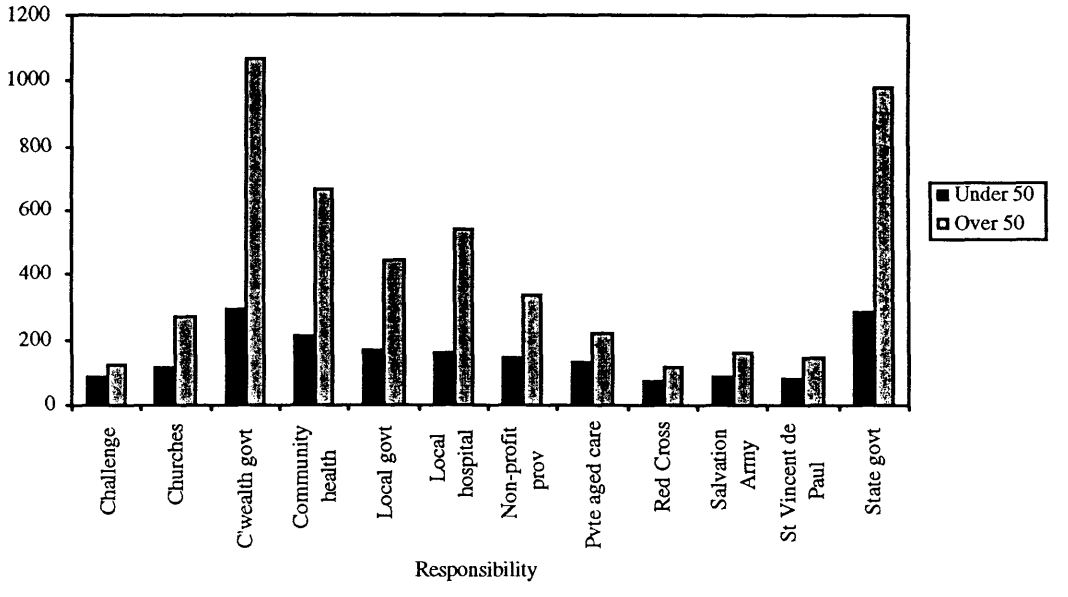

Figure 3.5: Responsibility for aged care services

Federal government	26%
State government	17.5%
State/Commonwealth government	12%
Local government	8%
All governments	13%

One lone respondent suggested that aged care was everyone's responsibility!

The *New South Wales Older People's Survey 1999* (NSW Health 2000) did not traverse issues of service responsibility but did ask older people what their aspirations were for the future. These are summarised as a desire to stay healthy and free from disability, to continue to live normally, and that they feared losing their health and independence.

Aged care industry issues

Focused interviews

Issues raised in qualitative interviews with senior managers in the aged care industry and local government representatives within the region identified the following issues that are confronting the industry:

- constant change
- achieving accreditation, maintaining and increasing quality
- financial issues — particularly the regular assessment of dependency of residents and the negative impact that has on funding where the dependency of the resident decreases
- professional recognition and status of staff and the industry particularly in respect to the public and private acute care systems
- compliance with regulatory requirements and the need for services to work together to respond to some of these requirements
- inter-agency and inter-government relations and the need to look to greater co-operation, partnerships and joint ventures
- training and education and its importance in maintaining and improving the quality of care and in raising the status and image of the industry
- structural issues that include the adequate size and nature of facilities and services, the future direction of service delivery to older people and how best

to survive and grow in a changing environment

- respite care adequacy for the aged and in particular for the carers of the aged, many of whom are old or approaching old age themselves
- meeting the specific needs of older disabled persons with physical and intellectual disabilities and dementia and the carers of these groups
- the value of the aged care assessment team (ACAT) and the need for it to be better resourced.

The contact with the aged care industry in the New England region was both positive and useful in understanding the above issues. The facilities visited were of a high standard with a good quality of service, and there was good co-operative effort throughout the industry, particularly through the regional grouping of the Aged and Community Services Association of NSW and ACT.

Industry forums

The Aged and Community Services Association of NSW is an industry body that represents predominantly the not-for-profit aged care residential and community care providers in New South Wales. Part of its role is to address on behalf of its rural members their concerns about the future viability of their services and of the perceived threat they feel to their viability through the development by NSW Health of multi-purpose centres in rural communities. These centres are meant to physically aggregate all health and aged care services to the one purpose-built facility, under the control and management of the relevant NSW Health Area Health Service. Despite flexible models in other states and the recommendations of the Sinclair Committee (2000), NSW Health has a 'one model fits all' approach to the development of multi-purpose centres.

To encourage debate about this issue and to develop new directions and models of care for rural communities, the Association conducted two rural forums entitled 'Think Tanks' for its members and invited participants. Each of these forums attracted about 40 participants, the first held at Dubbo, New South Wales, in September 2000 and the second in Tamworth, New South Wales, in May 2001. Preliminary drafts of this thesis were provided as a background document to the Dubbo forum, while the researcher participated in the Tamworth forum. This opportunity was taken to provide some validation to the research and findings prior to the completion of the thesis.

The conclusions from those forums recognise the need for change and new

models of care. The Dubbo Declaration (ACSA NSW 2001) was developed in the context of 'the new era of flexible care models' and also sought to 'help NSW Health to think through a consistent philosophy on rural aged care'. Models considered at the forum ranged from aged care providers operating local health services, to the multi-purpose service concept that was seen as an intermediary option as were other 'partnership/strategic alliances' which allowed the pooling and sharing of resources to deliver services.

The subsequent forum held in Tamworth in May of 2001 (ACSA NSW 2001) expressed disappointment with the lack of progress in the implementation of the Sinclair Report (2000) and in deliberations between the Association and NSW Health. The Association asserts that: 'Both Think Tanks (Dubbo and Tamworth) have helped ACSA become better informed about a greater range of models' (ACSA NSW 2001). These models include the complete takeover by an aged care centre of an ailing local hospital, and a three component model. In the three component model, the aged care centre that provides residential care is the hub for community care and shares long day, palliative care and rehabilitation with the hospital, which retains responsibility for acute and emergency care in facilities leased by the Area Health Service. Two further models include a co-operative arrangement where one entity provides shared services such as meals and maintenance to the other and a joint management model of an integrated health and aged care facility.

The strategy outcome of these two forums was:

> to reframe the rural aged care and health debate so as to enable the creation of flexible models of care and to ensure that ACSA members play a prominent role in the new debate and that their interests are catered for in the new models of care. (ACSA NSW 2001:2)

While the strategies themselves are commendable, they reflect the need to work within the constraints of control and ownership focus, and the unwillingness to properly engage the community, as described in earlier chapters of this thesis (Best 1999:2; Fennell & Flood 1998:424; Hindle 2000:3–8; Humphreys 1996:13; Strasser & Bryant 1999:9).

Again, and not unexpectedly, the focus of the debate at these forums has also been on stabilising by aggregation the existing range of services in rural communities that represents part of the possible solutions rather than also addressing potential innovative future directions identified by this and other research.