

The Senate

Community Affairs
References Committee

Quality and equity in aged care

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OVERVIEW

With Australia's population ageing, demand for aged care services will increase. This will require not only adequate facilities but a skilled and committed workforce. The aged care workforce is facing significant challenges: the lack of pay parity along with the requirements for paperwork means that nursing staff and personal carers are difficult to recruit and retain; the decrease in the number of nurses employed in the residential aged care sector can lead to inappropriate skills mix, increased stress and potentially a decrease in the quality of care; expansion of the community care sector has led to increasing demands for skilled workers; and poor pay for personal carers make it difficult to employ staff. There are fewer GPs providing services in residential aged care facilities as well as a lack of specialist geriatricians in residential services. These issues are exacerbated by the current general shortage of nurses and medical practitioners.

The problems within the aged care workforce are not new. While the Commonwealth and States and Territories have instituted a number of initiatives to address the nursing shortage, the Committee considers that more needs to be done, in particular, to increase the number of undergraduate nursing places and to assist additional enrolled nurses to complete medication management training. The scope of the new *National Aged Care Workforce Strategy* needs to be expanded to address the workforce needs of the whole aged care sector and mechanisms to address wage parity for nurses and personal care workers require further consideration.

The Aged Care Standards and Accreditation Agency plays an important role in assessing and monitoring the care, health and safety of residents in aged care facilities. While the standards of care in aged care facilities are generally adequate, the Agency needs to improve the monitoring of standards in homes especially through increased use of unannounced 'spot checks' of facilities. The Committee considers that the quality of care could be improved through the development of a benchmark of care which ensures that the level and skills mix of staffing in facilities is sufficient to deliver the care required and a review of the Accreditation Standards to define in more precise terms the 'outcomes' in providing care to the elderly. The Committee made recommendations towards improving the Complaints Resolution Scheme so that the Scheme is more accessible and responsive to complainants. The issue of excessive documentation and the need to reduce the administrative and paperwork burden on staff to enable them to concentrate on their primary task of delivering care and meeting residents' needs was also addressed.

There are currently over 6000 people aged under 65 residing in aged care facilities in Australia and many more young people are at risk of being placed in aged care facilities. An aged care facility is an unacceptable accommodation option in most instances for a young person: they do not support the social and emotional needs of young people; there is a lack of privacy and the lifestyle is highly regimented; in some

instances staff are not adequately trained to provide the complex care needs of young people; and there is a lack of services including rehabilitation.

The Committee considers that young people should be moved out of aged care facilities and into more appropriate accommodation. Differing models of care were raised with the Committee ranging from small cluster accommodation, to group homes, to support of the individual at home. The Committee had the opportunity to visit supported accommodation homes in Melbourne and Perth. The Committee considers that there is no one model of care suitable for every case but rather endorses an individual approach as each person will have different needs. Indeed, it may be appropriate for some young people to remain in an aged care facility and for access to services to be improved.

The Council of Australian Governments is to address the issue of young people in aged care facilities with Senior Officials to report on this matter by December 2005. The Committee considers that this is an important first step and has recommended that the Senior Officials clarify the roles and responsibilities of all jurisdictions in relation to young people in aged care facilities so as to ensure that age-appropriate accommodation options are made available; and funding is available for the provision of adequate services to those transferring out of aged care facilities.

The Committee has also recommended in relation to the Innovative Pool that the Commonwealth and State and Territory Governments work cooperatively to ensure that any barriers to accessing funds available under the Innovative Pool are removed so that the desired objective of moving young people out of residential aged care facilities into more appropriate accommodation is met.

The Committee has also made recommendations for the funding of the care of the frail elderly with special needs such as dementia and mental illness and as a result of long-term disability and homelessness.

Community care programs make a significant contribution in enabling older people to successfully live at home or in the community. While current programs provide valuable services to older people, significant reform is required to achieve a system that better responds to the needs of consumers, care workers and service providers. The current system is not providing adequate levels of service; services are fragmented; and there is a complex mix of services that are often difficult to access.

The Committee has made recommendations for increased funding for community care programs and for improved provision of services for special needs groups. The Committee also called for improved recognition of the role of carers in the informal care system – carers who form the 'backbone' of the community care system.

Care arrangements for the transition of the elderly from acute hospital settings to aged care settings or back to the community should ideally provide for a seamless continuum of care between the health and aged care sectors. The Committee found that while a number of initiatives have been undertaken at the Commonwealth and State levels towards improving current arrangements, there is a need for a more

coordinated approach between different levels of government and an urgent need to address a system that remains fragmented and ill-equipped to meet the particular care needs of the elderly. Recommendations are made to improve coordination between governments in the development and implementation of transitional care programs and to improve discharge planning from acute hospital settings and geriatric assessment.

RECOMMENDATIONS

Aged Care Workforce

Recommendation 1

2.97 The Committee welcomes the Commonwealth's allocation of 400 extra nursing places at universities in the 2004-05 Budget. However, the Committee recommends that the Commonwealth further increase the number of undergraduate nursing places at Australian universities to 1000 as recommended by the Hogan Review.

Recommendation 2

2.98 That the Commonwealth work with aged care providers to ensure that their shared responsibility to assist enrolled nurses to complete medication management training meets the target as recommended by the Hogan Review.

Recommendation 3

2.99 That the Commonwealth implement a strategy which allocates an appropriate number of undergraduate nursing places on the basis that recruitment for those places occurs from the current residential and community care workforce in both rural and urban settings proportionally.

Recommendation 4

2.100 That the Commonwealth investigate the effectiveness of incentives for staff to work in aged care settings in rural and remote areas.

Recommendation 5

2.101 That the Commonwealth, as a matter of priority, expand the National Aged Care Workforce Strategy to encompass the full aged care workforce, including medical and allied health professionals, and all areas of the aged care sector, in particular the community care sector.

Recommendation 6

2.102 That the Department of Health and Ageing and the Department of Education, Science and Training, as part of the National Aged Workforce Strategy, ensure the inclusion of quality aged care curricula in undergraduate nursing.

Recommendation 7

2.103 That the Commonwealth consider implementing mechanisms to ensure that the conditional adjustment payment aimed at restoring wage parity for nurses, personal carers and other staff in the aged care workforce is used to meet this aim.

The Accreditation Agency, Accreditation Standards and complaints resolution

Recommendation 8

3.37 That the Agency ensure that the training of quality assessors delivers consistency in Agency assessments of aged care facilities.

Recommendation 9

3.38 That the Agency publish data on the accuracy of assessors' decisions in conducting assessments against Agency benchmarks and that this data be provided in the Agency's annual report and on its website.

Recommendation 10

3.55 That the Agency further develop and improve information provided to residents and their families about the accreditation process, including those from CALD backgrounds and Indigenous people, and more actively involve residents and their families in the accreditation process.

Recommendation 11

3.56 That the Agency develop a rating system that allows residents and their families to make informed comparisons between different aged care facilities. The Committee notes that work is being done on a web-based prototype; however it considers that the rating system should not be limited to a 'star rating' but should include easily understood descriptions of a range of attributes, such as type and range of services provided; physical features of homes; staffing arrangements; costs of care; and current accreditation status.

Recommendation 12

3.74 That the Agency ensure that all facilities be subject to a minimum of one annual random or targeted spot check and at least one site visit with notification over its accredited period.

Recommendation 13

3.93 That the Agency, in consultation with the aged care sector and consumers, develop a benchmark of care which ensures that the level and skills mix of staffing at each residential aged care facility is sufficient to deliver the care required considering the needs of the residents. The benchmark of care that is developed needs to be flexible so as to accommodate the changing needs of residents.

Recommendation 14

3.125 That the Commonwealth, in consultation with industry stakeholders and consumers, review the Accreditation Standards to define in more precise terms each of the Expected Outcomes and that this review:

-
- address the health and personal care needs of residents, especially nutrition and oral and dental care; and
 - include specific consideration of the cultural aspects of care provision, including the specific needs of CALD and Indigenous residents.

Recommendation 15

3.126 That the Agency make greater use of interpreters during accreditation visits to aged care facilities, especially those facilities that cater for specific or predominant numbers of CALD or Indigenous residents; and that assessors be trained in cultural competency as part of their formal training courses.

Recommendation 16

3.154 That the Commonwealth review the operations of the Aged Care Complaints Resolution Scheme to ensure that the Scheme:

- is accessible and responsive to complainants;
- provides for a relaxation of the strict eligibility criteria for accepting complaints;
- registers all complaints as a complaint, with the complaints being categorised by their degree of severity, such as moderate level of complaint, complaints where mediation is required or where more significant levels of intervention are required; and
- provides that the mediation process is responsive and open and that sufficient support for complainants is provided in this process.

Recommendation 17

3.155 That the Commonwealth examine the feasibility of introducing whistleblower legislation to provide protection for people, especially staff of aged care facilities, disclosing allegations of inadequate standards of care or other deficiencies in aged care facilities.

Recommendation 18

3.173 That the Commissioner for Complaints conduct an investigation into the nature and extent of retribution and intimidation of residents in aged care facilities and their families, including the need for a national strategy to address this issue.

Recommendation 19

3.187 That the Agency's role in promoting 'best practice' continue and that it:

- develop a standard evidence-based approach to defining 'best practice' in aged care; and

- provide regular aggregated information to the industry on methods for achieving 'best practice' in the provision of aged care services.

The Committee further recommends that the Agency consider ceasing its direct role in providing direct staff training given the potential conflict of interest that this entails.

Documentation and Technology

Recommendation 20

3.217 That the Agency, in consultation with industry stakeholders and consumers, review the information required to be provided in the document *Application for Accreditation* and consider the feasibility of other options such as reporting by exception, with a view to reducing superfluous and time consuming reporting.

Recommendation 21

3.218 The Committee welcomes the Commonwealth's initiatives in promoting IT in the aged care sector and recommends that the implementation of these initiatives, as well as increasing the take-up rate, should be a matter of priority.

Young people in residential aged care

Recommendation 22

4.167 The Committee is strongly of the view that the accommodation of young people in aged care facilities is unacceptable in most instances. The Committee therefore recommends that all jurisdictions work cooperatively to:

- assess the suitability of the location of each young person currently living in aged care facilities;
- provide alternative accommodation for young people who are currently accommodated in aged care facilities; and
- ensure that no further young people are moved into aged care facilities in the future because of the lack of accommodation options.

Recommendation 23

4.168 The Committee notes that the Council of Australian Governments has agreed that Senior Officials are to consider ways to improve Australia's health care system, including helping young people with disabilities in nursing homes, and to report back to COAG in December 2005 on a plan of action to progress these reforms. The Committee recommends that the Senior Officials clarify the roles and responsibilities of all jurisdictions in relation to young people in aged care facilities so as to ensure that:

- age-appropriate accommodation options are made available; and

- funding is available for the provision of adequate services to those transferring out of aged care facilities.

The Committee supports every endeavour to reach a positive outcome.

Recommendation 24

4.169 That the Senior Officials' report to the Council of Australian Governments include:

- support for a range of accommodation options based on individual need;
- ways in which the successful accommodation and care solutions already in place can be extended to other jurisdictions;
- identification of barriers to the successful establishment of accommodation options and provision of adequate support services by all levels of government; and
- identify a timeframe for the establishment of alternative accommodation options and the transfer of young people out of aged care facilities.

Recommendation 25

4.170 That the Commonwealth and State and Territory Governments work cooperatively to ensure that any barriers to accessing funds available under the Innovative Pool are removed so that the desired objective of this initiative in providing alternative accommodation options for young people in aged care facilities is met.

Recommendation 26

4.173 The Committee recognises that in rare instances, a young person may choose to remain in an aged care facility. In such circumstances, the Committee recommends that the Commonwealth and the States and Territories work cooperatively to reach agreement on:

- an assessment tool to address the complex care needs of young people in aged care facilities;
- mechanisms, including a funding formula, to provide rehabilitation and other disability-specific health and support services, including specialised equipment; and
- ways to ensure that the workforce in aged care facilities caring for young people has adequate training to meet their complex care needs.

Recommendation 27

4.174 That the Department of Health and Ageing collect data on young people in aged care facilities by disability type.

Recommendation 28

4.176 That the Commonwealth and State and Territory Governments give priority to the efforts of the Working Party established in November 2004 to examine succession planning for ageing carers of children with disabilities and appropriate support for respite for carers.

Funding for aged care residents with special needs**Recommendation 29**

5.61 That the supplementary funding for aged care for residents with dementia be provided for by additional funding and not funding from within the current budget.

Recommendation 30

5.62 The Committee recognises that the Australian Health Ministers have jointly agreed to the development of a National Framework for Action on Dementia and that the Commonwealth has recognised dementia's significance with a \$320.6 million package of support over five years. The Committee recommends that all jurisdictions work together with providers and consumers to expedite the finalisation and implementation of the Framework to assist all dementia sufferers.

Recommendation 31

5.63 That the Commonwealth undertake a review of the additional costs of providing care for those with dementia and those needing palliative care to ensure that the new funding supplement will be sufficient to provide adequate care.

Recommendation 32

5.66 That the Commonwealth establish a funding supplement for residents in residential aged care who have additional needs arising from mental illness.

Recommendation 33

5.67 That the Commonwealth investigate the provision of psychogeriatric services and the effectiveness of psychogeriatric care units.

Recommendation 34

5.68 That the Commonwealth provide targeted funding for the education of the aged care workforce caring for people with mental illness.

Recommendation 35

5.70 That the Commonwealth establish a funding supplement for residents in residential aged care who have additional needs arising from homelessness.

Recommendation 36

5.74 That the Commonwealth respond to the growing needs of people ageing with disabilities by consulting with the States and Territories and stakeholders to identify ways to improve access by people ageing with a disability to appropriate aged care services including service provision in supported accommodation.

Community Care Programs**Recommendation 37**

6.20 That, while welcoming the increases in Commonwealth and State and Territory funding for the Home and Community Care Program over recent years, the Commonwealth and State and Territory Governments increase funding for HACC services to ensure more comprehensive levels of care can be provided to existing clients and to ensure sufficient growth in funding to match growth in demand.

Recommendation 38

6.21 That the Commonwealth review the indexation arrangements for the Home and Community Care Program to reflect the real costs of providing care.

Recommendation 39

6.33 That the Commonwealth and States and Territories substantially increase funding for identified special needs groups within the HACC target population including people from culturally and linguistically diverse backgrounds; Aboriginal and Torres Strait Islander people; people with dementia; financially disadvantaged people; and people living in remote or isolated areas.

Recommendation 40

6.34 That the HACC guidelines be amended to recognise homeless people or people at risk of homelessness as a special needs group.

Recommendation 41

6.35 That the Commonwealth introduce a funding supplement to reflect the additional costs of providing community care services in regional, rural and remote areas.

Recommendation 42

6.47 That, while welcoming the increases in Commonwealth funding for Community Aged Care Packages and Extended Aged Care at Home packages over recent years, the Commonwealth increase funding for these programs to meet demand for these programs and to provide viable alternatives to residential aged care.

Recommendation 43

6.67 That the Commonwealth provide a clearly defined timetable for implementing all aspects of *A New Strategy for Community Care: The Way Forward*.

Recommendation 44

6.68 That, in supporting the approach in *The Way Forward* for implementing a more streamlined and coordinated community care system, the Commonwealth address the need for improved service linkages between aged care and disability services.

Recommendation 45

6.69 That the Commonwealth and State and Territory Governments assess the appropriateness of the compulsory competitive tendering process for future programs as part of the implementation of *The Way Forward* strategy.

Recommendation 46

6.80 That *The Way Forward* implementation strategy recognise the central role of carers in the community care system.

Recommendation 47

6.81 That, while welcoming the increases in Commonwealth funding for carer-specific programs over recent years, the Commonwealth increase funding for these programs through the National Respite for Carers Program and the Carer Information and Support Program.

Transitional Care

Recommendation 48

7.58 That the Commonwealth and the States and Territories improve coordination in the development and implementation of transitional care programs, and that the development of programs include input from the community sector and health professionals.

Recommendation 49

7.59 That the results of innovative pilot programs funded by the Commonwealth and the States and Territories be widely disseminated and that mechanisms be developed to coordinate information about these pilots across jurisdictions so that innovative models of transitional care can be more readily developed based on these models.

Recommendation 50

7.60 That, the Commonwealth, in conjunction with the States and Territories, develop a national framework for geriatric assessment and discharge planning and the provision of post-acute and convalescent services and facilities, including

community services; and that discharge planning be coordinated across a range of medical, allied health and community care professions and involve the patient, their family and carers in the development of these plans.

Recommendation 51

7.61 That common assessment procedures for patients be implemented across the various health sectors so that medical records and diagnostic results can be easily transferred across these sectors.

CHAPTER 1

INTRODUCTION

Terms of reference

1.1 On 23 June 2004 the Senate referred the following matters to the Committee for inquiry and report by 30 September 2004:

(a) the adequacy of current proposals, including those in the 2004 Budget, in overcoming aged care workforce shortages and training;

(b) the performance and effectiveness of the Aged Care Standards and Accreditation Agency in:

(i) assessing and monitoring care, health and safety,

(ii) identifying best practice and providing information, education and training to aged care facilities, and

(iii) implementing and monitoring accreditation in a manner which reduces the administrative and paperwork demands on staff;

(c) the appropriateness of young people with disabilities being accommodated in residential aged care facilities and the extent to which residents with special needs, such as dementia, mental illness or specific conditions are met under current funding arrangements;

(d) the adequacy of Home and Community Care programs in meeting the current and projected needs of the elderly; and

(e) the effectiveness of current arrangements for the transition of the elderly from acute hospital settings to aged care settings or back to the community.

1.2 On 1 December 2004 the Senate agreed to the Committee's recommendation that the reference, not disposed of at the end of the 40th Parliament, be re-adopted with a reporting date of 23 June 2005.

Conduct of the inquiry

1.3 The inquiry was advertised in *The Australian* and on the Internet. The Committee invited submissions from Commonwealth and State Government departments and other interested organisations and individuals.

1.4 The Committee received 243 public submissions and 10 confidential submissions. A list of individuals and organisations who made a public submission or provided other information that was authorised for publication by the Committee is at Appendix 1.

1.5 The Committee held nine days of public hearings in Sydney – 19.8.04 and 11.3.05; Canberra – 11.2.05; Adelaide – 22.2.05; Perth 23.2.05; Brisbane – 18.3.05; Melbourne 26.4.05 and 27.4.05; and Hobart – 28.4.05. Witnesses who give evidence at the hearings are listed in Appendix 2. The Committee was pleased to undertake interesting and valuable inspections in Perth and Melbourne. In Perth, the Committee had the opportunity to visit the Multiple Sclerosis Society Wilson administration Centre and the 'Fern River' accommodation complex also at Wilson; the Brightwater Care Group facility for people with Huntington's Disease Ellison House in Carlisle and a group house in Maylands for people with Acquired Brain Injury. In Melbourne, the Committee visited the Multiple Sclerosis Society house in Carnegie that was a project developed with the assistance of Innovative Pool funding.

Acknowledgements

1.6 The Committee would like to record its thanks to Sue Shapland, Senior Manager of the MS Society WA; Janet Wagland, Services Manager for Younger People with the Brightwater Care Group; Lindsay McMillan, CEO and Alan Blackwood, Manager MS Society of Victoria; and Bronwyn Morkham, National Director National Alliance of Young People in Nursing Homes, who arranged the inspections of the respective facilities and who, in combination with other staff, accompanied the Committee members to explain the establishment, administration and operation of the facilities.

1.7 The Committee would like to particularly express its appreciation and gratitude to the residents of the different facilities that were inspected who permitted the Committee to visit their home and meet and talk with them.

1.8 The Committee also thanks the many individuals and groups who provided submissions that were such a valuable part of the inquiry including those who described the variable quality of care provided to their elderly family members. The Committee especially thanks the many individuals and family members who wrote submissions or appeared at the hearings and contributed very moving descriptions of their loved ones with disabilities either being accommodated in aged care facilities or being faced with that prospect due to the lack of alternative appropriate care.

1.9 These many graphic and poignant personal testimonies reinforced the Committee's view of the total unacceptability of placing younger people with disabilities into residential aged care facilities.

CHAPTER 2

WORKFORCE SHORTAGES AND TRAINING

Introduction

2.1 Issues surrounding workforce shortages and training in nursing, including the aged care sector, have been debated and reviewed for some time: there have been 34 reviews of nursing in seven years.¹ Indeed, in June 2002 this Committee tabled its report on its inquiry into nursing.² In the report the Committee noted the acute shortage of nurses in the aged care sector. The Committee pointed to evidence which indicated that delivery of quality care was under threat from the retreat of qualified nurses, both registered nurses and enrolled nurses, from the aged care sector. The Committee made a range of recommendations directed to improving recruitment and retention of nurses in the aged care sector including changes to workplace practices and at improving the image and training of nurses in the aged care sector.³

2.2 Evidence received during this inquiry suggests that there has been little improvement to the situation since 2002 with concerns being raised not only about the shortage of aged care nurses but also general practitioners with older persons' health expertise, geriatricians, psycho-geriatricians and allied health professionals.⁴ The challenge for the future is to ensure a skilled and committed workforce, able to meet the growing demand for services for ageing Australians.

The aged care workforce

2.3 The following provides an overview of trends in the aged care workforce from the *Review of Pricing Arrangements in Residential Aged Care Final Report* (Hogan Review)⁵:

- in June 2000, approximately 131 230 people, or 1.3 per cent of the Australian workforce were employed in the aged care industry;
- an estimated 32 628 people volunteered in aged care;
- between 1995-96 and 1999-2000, the number of employees in residential aged care declined while the number of people being cared for increased;

1 *Submission 73*, p.1 (Benetas).

2 Senate Community Affairs References Committee, *The Patient Profession: Time for Action: Report on the Inquiry into Nursing*, Canberra, June 2002.

3 *The Patient Profession*, pp.158-59.

4 See for example, *Submission 202*, p.8 (NSW Health).

5 Hogan WP, *Review of Pricing Arrangements in Residential Aged Care, Final Report*, Canberra, 2004.

- in accommodation for the aged (low care), the number of employees increased by 33 per cent; and
- between 1996 and 2001 the share of direct care provided by registered and enrolled nurses declined in both nursing homes and accommodation for the aged while the use of personal carers increased significantly.

2.4 The decline in employees in residential care was attributed to the decline in the use of staff not involved in the direct provision of care as a result of consolidation within the sector which enabled greater economies of scale; a greater reliance on outsourcing of some activities; and, greater use of multiskilling. The increase in the use of personal carers reflected both the growing shortage of nursing staff and the development of more efficient workforce structures.⁶

2.5 Australian Institute of Health and Welfare data on nursing shows that:

- in 2001 there were 19 109 registered nurses and 13 109 enrolled nurses employed in geriatrics/gerontology which represented 12 per cent of all registered nurses and 31.2 per cent of all enrolled nurses;
- between 1997 and 2001, the number of nurses working in geriatrics/gerontology declined 8.7 per cent;
- nursing homes and aged care accommodation accounted for 14.6 per cent of all nurses – the second largest proportion;
- the number of nurses working in nursing homes and aged care accommodation declined by 28.0 per cent between 1995 and 2001; and
- nurses working in nursing homes and aged care accommodation tended to be older than nurses in other work settings and they worked shorter hours.⁷

2.6 The National Institute of Labour Studies (NILS) report, *The Care of Older Australians: A Picture of Residential Aged Care Workforce*, stated that 'the existing level of knowledge about workers in aged care is remarkably limited' and no single data source provides an accurate and detailed appraisal of direct care employment in residential aged care, especially to inform complex workforce planning. The Report stated that, in 2003, there were 116 000 direct care employees of whom 25 000 were Registered Nurses, 15 000 were Enrolled Nurses, 67 000 were Personal Carers and 9 000 were Allied Health workers. NILS stated that 'there are few signs that this is a labour market in crisis, or even under serious stress' but went on to note that there were some indications of stress. These included that nurses are substantially older than the typical female worker, the relatively high number of vacancies for Registered Nurses and the high levels of turnover of direct care staff.⁸

6 Hogan Review pp.219-221.

7 AIHW, *Nursing Labour Force 2002*, AIHW, pp.3, 13-15, 20-21.

8 Richardson S & Martin B, *The Care of Older Australians: A Picture of the Residential Aged Care Workforce*, National Institute of Labour Studies, 2004, pp.1-5.

Issues facing the aged care workforce

There are a range of significant workforce issues in the aged care sector. Serious staff shortages, especially of qualified nurses and allied health professionals, are widespread. We experience continuous difficulty in recruiting qualified staff because of shortages and the necessity to compete with the acute sector that has a capacity to remunerate at much higher levels. Too much paperwork leads to staff burnout as dedicated staff struggle to maintain levels of care while dealing with burdensome documentation requirements. There is no real measure of the actual staff requirements for residential care.⁹

Nursing staff

2.7 The general shortage of nurses is impacting on the aged care sector. The Hogan Review stated that the shortage of nurses was greater in the residential aged care sector than in other areas of the health system.¹⁰ Even though there is a general shortage, some areas are more acute with the Queensland Government pointing to shortages of psychogeriatric nurses and aged care nurses in rural and remote communities, including Indigenous communities. In the future staff shortages will be exacerbated as the present residential aged care workforce is ageing and there are high levels of casualisation in the sector.¹¹

2.8 Witnesses stated that the barriers to recruitment, retention and re-entry of nurses to the aged care nursing were well known and include:

- lack of wage parity;
- inadequate staffing levels;
- inappropriate skills mix;
- workload pressure;
- increased stress levels; and
- an inability to deliver quality care.¹²

2.9 The lack of wage parity was seen as a major barrier. Witnesses indicated that there were still significant differences in wages between aged care nurses and those working in other sectors.¹³ The Queensland Nurses Union (QNU) pointed to differences in maximum and minimum wages in Queensland in 2004 ranging \$68.06 per week (13.3 per cent) for an assistant in nursing to \$93.98 per week (15.7 per cent) for Enrolled Nurses and from \$165.35 to over \$300 for Registered

9 *Committee Hansard* 11.2.05, p.2 (UnitingCare).

10 Hogan Review, p.221.

11 *Submission* 193, p.5 (Queensland Government).

12 *Submission* 179, p.2 (NSW Nurses Association).

13 *Submission* 73, p.1 (Benetas).

Nurses levels 1 to 5.¹⁴ The ANF commented that the wage disparity has been progressively widening as nurses in the private and public acute sectors have secured superior outcomes through enterprise bargaining. As at April 2004 the wage disparity stood at 21.6 per cent.¹⁵ As a consequence, the aged care sector is struggling to be competitive both in relation to wages and career opportunities for staff.

2.10 Evidence pointed to changes in staffing levels impacting adversely on the aged care workforce. The QNU stated the lack of accountability in the private sector has led to the erosion of staffing levels, with many employers continuing to cut nursing hours. The QNU commented that it was assisting members in facilities where this is occurring. Members in those facilities reported that their workloads were already unsustainable even prior to any cuts being implemented. Unpaid overtime was worked to complete duties.¹⁶ Witnesses also noted that the changes to staffing levels are being made when the dependency levels in residential aged care facilities has risen, with the number of residents receiving high level care increasing from 58 per cent in 1993 to 63.6 per cent in 2002.¹⁷

2.11 The shortage of nurses and other workers also raised occupational health and safety concerns. Many submissions pointed to the high incidence of injuries in the aged care sector. The QNU stated that nursing homes alone account for 10.3 per cent of injuries in the Health and Community Services Sector, with increased workloads correlating to increased injury rates.¹⁸ Nurses often work through breaks and find it difficult to comply with manual lifting policies that, for example, require two staff to perform resident transfers. Excessive workloads lead to shortcuts being taken. This adds to the stress of staff who cannot deliver quality care to residents.

2.12 Dr K Price of the Centre for Research into Sustainable Health Care also noted that employers are reticent to employ older workers because of their age. Research had indicated that aged care employers considered that older workers were at risk of injury and were using occupational health and safety laws not to employ older workers.¹⁹

2.13 Inadequate skills mix was another continuing and major concern. It was noted that there had been substantial substitution of personal carers for nurses in recent years. The ANF (Victoria) commented that in Victoria the skills mix of Registered Nurses (RNs) to residents had fallen from an average of 1 RN to 30 residents across all shifts in 1997 to 1 RN to 60 residents during the day, out to 1 RN to 90 or 120 at the evening and night shift. Some high care facilities only employ a registered nurse

14 *Submission* 186, p.5 (QNU); see also *Submission* 95, p.7 (QNC).

15 *Submission* 201, p.7 (ANF)

16 *Submission* 186, p.7 (QNU).

17 *Submission* 201, p.6 (ANF).

18 *Submission* 186, p.8 (QNU).

19 *Committee Hansard* 22.2.05, p.20 (Centre for Research into Sustainable Health Care).

for two two-hour shifts per day – to administer medications. The ANF (Victoria) noted that these facilities still meet accreditation standards.²⁰

2.14 Dr Price also commented:

...we limit the number of RNs, we limit the number of ENs and we put in care workers with only a certificate 3 at the most – and we expect to get a workforce. Why should an RN go into a workforce where he or she knows that they are going to be the only one on for 60 residents? Why should somebody? We have to stop it at some point. There should be many more. There is a one to five ratio in acute care: why isn't there that ratio in aged residential care?²¹

2.15 While not opposing the use of personal carers, the ANF commented that it was opposed to the replacement of registered and enrolled nurses with unlicensed workers 'where the work requires the skills and knowledge of either an enrolled or registered nurse'. Unlicensed nursing and personal carers generally are competent but they are not able to always recognise serious problems including changes in the health status of residents and they require supervision and support from registered nurses.²²

2.16 As a result of these changes, registered nurses in aged care workplaces are facing increases in spans of responsibility and associated difficulties in adequately supervising other staff, including staff with lower qualifications. The QNU stated that 'these factors are significant influences on why registered nurses are leaving and are not being attracted to work in aged care services'.²³ Skills mix is discussed further in Chapter 3.

2.17 The level of paperwork remains an issue for nurses.²⁴ ANHECA commented that one of the major reasons given for registered nurses leaving the residential care sector or declining to enter the sector is the sheer volume of paperwork required of registered nurses working in residential care.²⁵ Witnesses commented that excessive paperwork is required to validate appropriate resident classification for the Resident Classification Scale (RCS) funding scheme, accreditation processes and the complaints resolution scheme. Nurses were spending valuable time 'form filling' rather than providing hands-on nursing care. The issue of excessive documentation is addressed in the Chapter 3.

20 *Submission* 66, p.1 (ANF Victoria).

21 *Committee Hansard* 22.2.05, p.23 (Centre for Research into Sustainable Health Care).

22 *Submission* 201, p.17 (ANF); see also *Submission* 127, p.3 (AMNC).

23 *Submission* 186, p.9 (QNU).

24 *Submissions* 71, p.4 (RCNA); 95, p.8 (QNC).

25 *Submission* 74, p.3 (ANHECA).

Personal carers

2.18 The Health Services Union (HSU) and the Liquor Hospitality and Miscellaneous Union (LHMU) drew the Committee's attention to significant issues for personal carers in the aged care sector. Personal carers received relatively low wages. The HSU (NSW) stated that a carer with a Certificate III in Aged Care earns \$13.53 per hour. The hourly rate is less than that of checkout operators in supermarkets but requires TAFE certificate qualifications in aged care. Carers are required to provide a range of personal care services, with minimal supervision as well as simple health needs such as wound dressing, attend to blood pressure, and temperature and pulse checks. As a result, it is extremely difficult to attract and retain younger staff.²⁶

2.19 The Brotherhood of St Laurence also noted that personal carers in the community work in relative isolation which makes it difficult to attract and retain workers. Of particular concern was the lack regular support and supervision for many workers. Many organisations provide only limited support to workers to undertake training – in some cases all training costs, including time, are borne by the worker.²⁷

2.20 Staffing shortages also impact on personal carers and the level of care they can provide to residents. The HSU stated that its members reported that because of understaffing they only have time to provide 'basic care' to residents and regret that the feeding and showering of residents is too often 'like a production line'. In some instances, basic hygiene suffers with residents going without showers, teeth not being brushed and hair not combed or washed.²⁸ The LHMU indicated that at one facility it was reported that three care workers had 60 minutes to get 49 residents out of bed, showered, dressed and into the dining room for breakfast.²⁹

2.21 Of serious concern to members of the HSU was understaffing at night. It was stated that it is not uncommon for one carer to be rostered on alone overnight in a hostel looking after up to 50 residents. If an emergency occurs there is no backup. For example, if a resident falls the carer is often physically unable to assist the resident off the floor and back into bed. In such cases, carers will either call an ambulance to assist or make the person comfortable on the floor until morning when more staff arrives.³⁰

2.22 Because of staff shortages, the HSU stated that carers are often required to work double shifts. Unpaid overtime is also worked by carers to fulfil their own sense of obligation to frail residents.³¹ This contributes to stress and fatigue. The HSU also

26 *Submission 59*, p.4 (HSU NSW); see also *Submission 122*, p.5 (HSU).

27 *Submission 52*, p.2 (BSL).

28 *Submission 122*, p.4 (HSU).

29 *Submission 124*, p.6 (LHMU).

30 *Submission 59*, pp.8-10 (HSU NSW).

31 *Submission 124*, p.7 (LHMU).

voiced concern that staff shortages contributed to safety problems for staff, citing cases of assaults by intruders at aged care facilities.³²

Community care

One of the things that we are now seeing is a reluctance of people to take up work in the community sector. I get a sense from within my own membership that the community care work force is in – I hate using the word 'crisis' – peril of leaving a good number of people in their homes without ongoing support if we as a nation do not do something to enhance the benefits that community care workers get to make it an attractive field of endeavour for workers to work in. That is the community care aspect.³³

2.23 In the community care sector there is increased demand for workers as the sector is experiencing significant growth. The Queensland Government stated that the three drivers in the size and occupational distribution of the workforce were seen as: the rate of funding growth in community aged care programs and related areas; increased reliance on the paid care workforce as opposed to the volunteer workforce; and the preference of many older people who have significant impairments to stay at home.³⁴

2.24 All States and Territories are experiencing rapid growth of community care programs in both ageing and disability. In Queensland, for example, HACC has had an average growth of around 10 per cent per annum over the past five years. At the same time Community Aged Care Packages have grown at a rapid rate and a number of other programs have either been initiated or expanded, most notably Veterans Home Care and the Extended Aged Care at Home (EACH) program. As a result, demand for a skilled workforce has increased.³⁵

2.25 The expansion of disability programs which employ people with similar skills for similar tasks such as personal care (eg help with toileting, showering and dressing) means that there is a competitive market for trained staff. NSW Health commented that there are staff shortages for community care services for older people, particularly for nurses and therapists. The impact is that older people may not receive appropriate community care services.³⁶

2.26 Workers in the community care workforce are often part time or casual workers or contractors. It was reported that there is a high turnover of workers which poses difficulties for staff replacement, especially in rural areas. Reasons given for the high turnover include low pay, lack of career path, having to work in relative

32 *Submission 122*, p.8 (HSU).

33 *Committee Hansard 22.2.05*, p.1 (ACS SA & NT).

34 *Submission 193*, p.5 (Queensland Government).

35 *Submission 193*, p.5 (Queensland Government).

36 *Submission 202*, p.10 (NSW Health).

isolation, occupational health and safety challenges associated with working in the client's own home and the age profile of the community care workforce.³⁷

2.27 It was also stated that there is evidence that many organisations which relied on volunteers to provide services such as day respite programs, meals on wheels, social support and transport are finding it difficult attract volunteers. Organisations are also finding that they must employ more staff as there is increased demand to provide more services, to improve quality and to deliver on compliance obligations such as meeting standards, entering client information on data bases and preparing reports to funding agencies.

2.28 As more people are now opting to stay at home for longer as they age, greater numbers of extremely frail older people who have significant dependencies and complex service requirements are living in the community. To ensure that older people can live at home safely, requires a more highly skilled workforce.

2.29 The Queensland Government noted that 'there is a paucity of information about the community care workforce'. There is no comprehensive data source available for the community aged care workforce in Queensland that would enable Queensland Health to identify shortages of skilled staff, turnover rates, or occupational categories/geographic areas where shortages are particularly severe. The Government suggested that this would appear to be a national issue where the Commonwealth Government could take an important leadership role as it is the primary funder of community aged care programs.³⁸

Medical practitioners and allied health professionals

2.30 The Australian Medical Association (AMA) indicated that there had been a decline in the number of general practitioners visiting residential aged care facilities. The AMA stated that there were a number of barriers to health professionals visiting residential aged care facilities including the absence of appropriate Medicare Benefits Schedule items for geriatricians, the large amount of paperwork expected of GPs and staff of the facilities and the lack of integration of medical services in the aged care system.³⁹

2.31 The Victorian Government also commented on the role of GPs and noted that, although the GP workforce does not strictly form part of the aged care workforce, GP workforce shortages have contributed to the decline in Medicare Benefit Schedule funded services provided to people in residential care. The Government welcomed the Commonwealth's plan to enhance GP services for older people by introducing a new Medicare rebate for GPs to visit aged care facilities to provide a comprehensive

37 *Submission 125*, p.2 (ACS SA & NT).

38 *Submission 193*, p.6 (Queensland Government).

39 *Committee Hansard 11.2.05*, p.21 (AMA); see also *Committee Hansard 22.2.05*, p.14 (Resthaven); p.54 (Adelaide North East Division of General Practice).

assessment of residents' health and funding to Divisions of General Practice to establish panels of GPs for residential aged care facilities in their area.⁴⁰

2.32 In relation to specialist care, the AMA stated that consultant physicians in geriatric medicine were best placed to provide specialist aged care advice and education across the whole continuum of care. However, 'government health programs such as the existing Medical Benefits Schedule (MBS) structure and the MedicarePlus initiatives economically marginalise the geriatric medical workforce and restrict the provision of private hospital, community and religious specialist aged care'.⁴¹

2.33 The Australian Society of Geriatric Medicine also commented on the lack of geriatricians and other specialists working in aged care facilities.⁴² Most consultant physicians in geriatric medicine working in Australia work in the public hospital system. The AMA commented that this means that 'despite the clear health needs and the increasing numbers of older people in our community, those other than in public hospitals have limited access to the type of specialist aged care expertise that geriatricians and consultant physicians specialising in aged care can provide'. Ways to train and attract more consultant physicians to geriatric medicine, to make the most of their time and to involve the GP and other health professionals in more integrated team approaches are needed. The AMA concluded that a key to this development is the MBS items, which encourage GPs to work in aged care settings and for geriatricians to provide core geriatric medical services.⁴³

2.34 NSW Health indicated that with the exception of paediatrics, NSW has existing or emerging shortages in 24 key medical workforce groups. Geriatric medicine is one of the specialties in shortage. To address all of these shortages, 'every State and Territory Government needs to negotiate training plans and numbers for medical specialty trainees based on workforce requirements' with the medical colleges. The NSW Government has already begun this process through their negotiation with the Royal Australian College of Physicians on basic physician training. NSW Health commented that this new system is based on a number of principles that ensure trainees are equitably distributed across the State at the same time as improving their training experience.⁴⁴

2.35 Another area of concern was the lack of specialist and generalist nutritionists and dietitians. Metropolitan Domiciliary Care noted that 'good nutrition is particularly important for older people to maintain an independent lifestyle for as long as possible and to minimise morbidity and premature death'.⁴⁵ It also stated:

40 *Submission* 180, p.3 (Victorian Government).

41 *Committee Hansard* 11.2.05, p.22 (AMA).

42 *Committee Hansard* 19.8.04, p.35 (ASGM).

43 *Committee Hansard* 11.2.05, p.22 (AMA)

44 *Submission* 202, p.9 (NSW Health).

45 *Committee Hansard* 22.2.05, p.40 (Metropolitan Domiciliary Care).

A network of specialist and generalist nutrition workers is needed in the public health system to initiate support and help sustain healthy ageing initiatives which are centred on nutrition. We are finding that the initiatives the organisations want to take are not able to be supported because the specialist nutrition workforce or generalist workers who have some experience in that area are just not there...There is an insufficient nutrition workforce that is adequately skilled and actively engaged in the aged care setting.⁴⁶

Commonwealth Government Programs and Initiatives

2.36 The Commonwealth has recognised the need to address the shortage of nurses, including aged care nurses. The Department of Health and Ageing (DoHA) provided these recent initiatives directed at aged care workforce issues:

- The Aged Care Workforce Committee: established in 1996 with representatives of peak organisations, aged care employees, approved providers, higher education and vocational education providers, professional groups and consumers. The Committee has assisted in identifying workforce issues and is developing a framework to respond to current and future issues.
- The National Aged Care Workforce Census and Survey: the Commonwealth, in partnership with the Aged Care Workforce Committee, has commissioned a national census and survey of the residential aged care workforce. The results of the study, which was undertaken by the National Institute of Labour Studies at Flinders University, are contained in the report *The Care of Older Australians: A Picture of the Residential Aged Care Workforce*. Major findings include that the workforce is well qualified, the overall vacancy rate and the vacancy rate for each major occupation was not high, but there was some difficulty in recruiting nurses and the overall shortage of registered nurses is affecting the aged care workforce.
- *The Recruitment and Retention of Nurses in Residential Aged Care*, published in 2002, was commissioned by the Commonwealth from La Trobe University. It identified several solutions to improve the recruitment and retention of nurses in the aged care sector. The Commonwealth response included a number of workforce initiatives.
- Nurse Practitioners in Aged Care: the Commonwealth, with the Aged Care Workforce Committee, is investigating opportunities to support trials for nurse practitioners within the aged care sector in recognition of the importance of professional development and career paths for registered nurses in aged care. ACT Health will conduct a trial over a 12-month period and cover residential, community and acute care settings.
- Nurse Re-entry Programs: the Commonwealth is funding several aged care specific nurse re-entry program pilots. The aim of the programs is to prepare

46 *Committee Hansard* 22.2.05, p.41 (Metropolitan Domiciliary Care).

former nurses for employment in the aged care sector, by offering them aged care nursing courses to encourage them to return to practice in rural and regional aged care services.

- Rewarding Best Practice: Good practice in recruitment and retention of skilled staff has been encouraged and rewarded through the Minister's Awards for Excellence in the Aged Care Industry and the Better Health and Safety Awards.

2.37 DoHA also provided information on initiatives in training, both general nurse training and specific aged care nursing training. The Commonwealth has funded the Aged Care Undergraduate Nursing Principles Project, which was conducted by the School of Nursing at the Queensland University of Technology. The resulting *Aged Care Core Component in Undergraduate Nursing Principles Paper* outlines a number of matters including the core values underpinning the learning and teaching of aged care; desirable learning outcomes; and principles for the learning and teaching of aged care.

2.38 In July 2004, the Commonwealth announced new university undergraduate nursing places. In the 2002-03 Budget, the Commonwealth provided \$26.3 million over four years to support and encourage more people to enter and re-enter aged care nursing, particularly in rural and regional areas. Approximately \$7 million of this funding was for the More Aged Care Nurses Scholarship Scheme. Under this initiative up to 1,000 aged care nursing scholarships, valued at up to \$10 000 a year, are being provided. More than 900 have already been awarded for undergraduate study, continuing professional development, honours courses and re-entry programs. The Commonwealth also provided funding to ensure that care staff employed in smaller and less viable aged care homes were provided with appropriate training opportunities.

2.39 In the 2002-03 Budget, the Commonwealth increased residential aged care subsidies by \$211 million over four years. DoHA stated that an important aim of this funding was to assist employers of aged care workers with the recruitment and retention of quality staff by offering increases in wages and improved working conditions.⁴⁷

2004-05 Budget initiatives

2.40 In the 2004-05 Budget a further \$101.4 million was allocated over four years to assist the aged care sector workforce. Initiatives included in this package, *Better Skills for Better Care*, were aimed at:

- assisting up to 15 750 aged care workers to access recognised education and training opportunities such as Certificate III or IV in aged care, or enrolled nurse qualifications;

47 *Submission 191*, pp.19-25 (DoHA).

- assisting up to 5,250 enrolled nurses to access recognised and approved medication administration education and training programs;
- assisting up to 8,000 aged care workers to access the Workplace English Language and Literacy program (WELL); and
- allowing more than 1,700 students to commence nursing studies over the next four years.

The funding for vocational education and training and medication management training places will be provided to eligible aged care providers to purchase the training directly.⁴⁸

2.41 In the 2004-05 Budget and in response to the Hogan Review, the Commonwealth provided additional funding of \$877.8 million over four years for a conditional adjustment payment. This funding was aimed at assisting aged care providers to continue to provide high quality care for older people, including assisting in paying more competitive wages to nurses and other staff. In order to qualify for the payment, aged care providers will be required to encourage staff to undertake training, publish audited financial statements and participate in periodic workforce surveys.

2.42 The Department noted that with the ageing population, there will be increasing demand for aged care nurses across all health sectors, including in hospital and community settings.⁴⁹ The Department stated that the Commonwealth had recognised the workforce issues in aged care and has implemented a strategic approach in meeting the challenges. It has 'demonstrated its commitment to the aged care workforce through significant budget investments in training and education for aged care workers, policy and research initiatives and trailing innovative programs in partnership with the aged care sector'. In addition:

The role of government is not confined to the federal sphere: state and territory governments, and local governments, all have critical roles, in policy and service delivery. A nationally consistent scope of practice for enrolled nurses, for example, depends on state and territory legislation.

Our whole community also has an important role to play, particularly in valuing older people and the people who care for them: the image of aged care continues to represent a major obstacle to recruitment and retention in the aged care workforce.⁵⁰

National Aged Care Workforce Strategy

2.43 In April 2005, the National Aged Care Workforce Strategy was released. The Strategy was developed by the Aged Care Workforce Committee following consultation with the aged care sector. The Strategy identifies the workforce profile of

48 *Budget Measures 2004-05*, Budget Paper No.2, p.186.

49 *Submission 191*, p.19 (DoHA).

50 *Submission 191*, p.26 (DoHA).

the residential aged care sector and its needs until 2010. The Minister for Ageing, the Hon Julie Bishop, stated that:

In coming years, we will not only have more older Australians, but more people who are frail, as well as new patterns of disease and disability. We will need a skilled, professional and flexible workforce to provide more services, better quality services and more service choices to the growing number of older people.⁵¹

2.44 The Strategy aims to provide a people management and development framework for a sustainable and viable aged care sector. The Strategy is made up of seven objectives and 17 strategies. The objectives include workforce profile, education, training and development, a responsive workforce and status and image.⁵²

2.45 It was noted that the Strategy focuses on the residential aged care workforce and that further work will be needed to broaden the strategic response to cover the full aged care workforce in all settings. The Productivity Commission is to undertake a study of the economic and fiscal implications of the future ageing of Australia's population on the labour supply and to examine the issues impacting on the health workforce. The Commission's findings will influence the implementation of the Strategy.⁵³

State Government initiatives

2.46 In addition to Commonwealth Government initiatives to address workforce issues in the aged care sector, State and Territory Governments have instituted programs to strengthen the aged care workforce. For example, in Victoria the HACC Workforce Development Strategy Project aims to improve the recruitment, retention and training of community case workers, increase the diversity of the HACC workforce and enhance professional development opportunities for staff. Aged care training has been enhanced through the Office of Tertiary and Training Education and the New Apprentice Trainee Completion Bonus scheme. In addition, a pilot project to increase the number of geriatric medicine trainees has been launched.⁵⁴

2.47 Queensland Health has also instituted a program to improve recruitment of nurses to aged care work. This includes an initiative which funds and supports placements for new graduates across the aged care continuum (acute, community, residential aged care); the Transition to Practice training program; and trialing the Nurse Practitioner in Aged Care settings. Queensland Health is also developing a HACC Workforce Skills Development Strategy to develop a framework for the skills

51 The Hon Julie Bishop, Minister for Ageing, 'Planning the future of the aged care workforce', *Media Release*, 21.4.05.

52 Aged Care Workforce Committee, *National Aged Care Workforce Strategy*, Canberra, March 2005, pp.v-vii, 3.

53 *National Aged Care Workforce Strategy*, pp.v-vi.

54 *Submission 180*, p.4 (Victorian Government).

development of the HACC workforce in Queensland. This will help develop an appropriate minimum level of skill in areas identified as essential to the provision of quality services. The Strategy will be implemented over a three year period between July 2005 and June 2008.⁵⁵

Impact of Commonwealth Government initiatives and programs

The federal budget of 2004 was a defining moment for the aged care sector. However, much more must be done and further guarantees need to be given that people accessing aged care services will not be disadvantaged by changes and reforms to aged care.⁵⁶

Geriaction therefore believes that the 2004-5 Budget initiatives will have virtually no impact on age care workforce shortages. While the training initiatives are welcomed this organisation believes they will have limited impact on the current workforce situation. These appear to be little more than bandaid measures that fail to address the need for a comprehensive workforce planning strategy. Only with workforce planning will the sector be able to develop recruitment, retention, and training strategies that will deliver quality outcomes over the long-term.⁵⁷

2.48 Many witnesses welcomed the Commonwealth's initiatives in the aged care sector. However, it was generally considered that some of the initiatives would not achieve their objectives and some areas require further work.⁵⁸

Nurse education and training

Undergraduate education

2.49 The Commonwealth has, over a number of years, provided additional funding for undergraduate nursing places. In the 2004-05 Budget, funding was allocated over four years to enable 1 700 additional students to commence undergraduate nursing with a focus on aged care. In addition, the Aged Care Nursing Scholarship and Support Scheme provides funding for undergraduate study, continuing professional development, honours courses and re-entry programs.

2.50 While the increase in the number of nursing places was welcomed, witnesses expressed doubts that the increase would provide a long term solution to the workforce problems facing the aged care sector. Witnesses pointed to the Hogan Review's recommendations for increases in the number of registered nurse places at Australian universities and the 2004-05 Budget response:

55 *Submission* 193, p.8 (Queensland Government).

56 *Committee Hansard* 11.2.05, p.3 (CHA).

57 *Submission* 88, p.1 (Geriaction).

58 *Submissions* 71, p.3 (RCNA);

Hogan Review Recommendations	Budget Response
Registered nurse places: 2700 over three years	Registered nurse places: 1094 over four years
1000 in 2004-05	400 in 2004-05

The Hogan Review recommended that these additional places should only be made available to universities which offer specialist training for aged care nurses.⁵⁹

2.51 UnitingCare commented:

What the government provided in the budget in response to that review was approximately half the level of training and places requested in the Hogan review. Whilst I think that it is great that the government is moving towards a better career path, better training, more places for the nursing industry and the enrolled nurses and carers generally, there needs to be more. I think Hogan probably got it fairly right.⁶⁰

2.52 The ANF also stated:

The Australian Government has increased undergraduate nursing course places in universities but the number allocated falls well short of what the industry needs. Both the National Review of Nursing Education and the Hogan report called for far greater numbers of undergraduate places. The ANF has estimated that 1100 extra places per year for four years is necessary to adequately address the nursing shortage.⁶¹

2.53 While expressing concern at the shortage of nurses, NSW Health noted that the NSW State Government has limited influence over the number and type of education and training places that are established in the higher education sector. It argued that it is critical that better linkages between the health, education and training sectors are established to ensure that the right number and type of health professionals are available to meet community need. It was noted that the greatest workforce pressures are in rural, regional and outer metropolitan regions and more HECS funded places for nurses, doctors, dentists and allied health staff in these workforce pressure areas are needed, as well as incorporating more targeted rural clinical placements into curricula.⁶²

2.54 Witnesses argued that with the general shortage of nurses, the increase in places would not keep pace with the demands of the acute sector let alone those of the

59 Hogan Review, p.xix.

60 *Committee Hansard* 11.2.05, p.7 (UnitingCare).

61 *Submission* 201, p.20 (ANF).

62 *Submission* 202, p.9 (NSW Health).

aged care sector. The poor image of aged care nursing arising from pay disparity, poor working conditions and lack of access to education and training made it a less attractive option for graduates and there was no guarantee that the new graduates would enter the aged care sector. This concern was highlighted by Aged and Community Services SA &NT which commented that in South Australia in 2003, all registered nurse graduates were absorbed into the public health system, private acute system or nursing agencies with no graduates entering aged care as a professional choice.⁶³ The aged care sector is a less popular area of practice and with competition from other areas witnesses believed that the shortages would continue.⁶⁴

2.55 It was also noted that demand for nursing staff was increasing across the health spectrum. However, in the aged care sector factors such as the increasing frailty of those entering residential aged care, the increasing number of aged care places and the larger numbers of nurses facing retirement because of the age profile of the aged care nursing workforce, means that demand may be higher than other sectors. Providers will need to employ larger numbers and more highly skilled registered nurses if the quality of care is to be maintained.⁶⁵ However, the Royal College of Nursing commented that the Budget initiatives focused on lower level nursing education at the expense of specialist gerontological nursing education.⁶⁶

2.56 Clinical placements for undergraduates was another area of concern. NSW Health argued that offering clinical placements in areas of workforce demand such as rural, regional and outer metropolitan areas is critical. The quality of the clinical placement experience impacts upon recruitment, particularly in areas such as aged care. NSW Health stated that the Commonwealth 'needs to acknowledge that clinical placements are significantly under-funded through the education sector and that this under-funding results in greater difficulties with recruitment and retention of the workforce'.⁶⁷

2.57 The Tasmanian Government also focussed on clinical placements for undergraduates and noted that if students do not have a positive experience whilst on placement in an aged care facility, they will be unlikely to seek future employment in the sector. It argued that scholarships to support work in aged care must be provided in conjunction with quality clinical placements. This is particularly the case given that there is no obligation for recipients to fulfil a period of employment in an aged care facility following admittance to the Bachelor of Nursing degree.⁶⁸

63 *Submission* 125, p.3 (ACS SA & NT).

64 *Committee Hansard* 27.4.05, p.51 (Royal District Nursing Service).

65 *Submission* 150, p.5 (VAHEC).

66 *Submission* 71, p.2 (RCN).

67 *Submission* 202 p.9 (NSW Health).

68 *Submission* 200, p.3 (Tasmanian Government).

Articulation between nursing levels

2.58 The Commonwealth's response to the Hogan Review provides for 4,500 additional vocational training places to be created each year for aged care workers to improve quality of care and to provide better career pathways for aged care workers. These places are aimed at assisting 15 750 aged care workers undertake vocational education training over the next four years. The funding for vocational education and training will be provided to eligible aged care providers to purchase the training directly. DoHA noted that the initiative 'will be largely focused towards certificates III and IV in aged care, with some possibility of training options for people to do diplomas to reach enrolled nurse level'.⁶⁹

2.59 The HSU noted that 80 per cent of the people who directly look after residents in aged care are carers, not nurses.⁷⁰ The level of training of carers varies significantly. The HSU stated that providers can and do use staff who have no training in aged care, with some even working alone at night. One carer stated:

Personal carers come in and I cannot understand how on earth they got their certificate. Their basic English is not very good and nor is their understanding of looking after somebody. When you orientate them, although they have just got their PC 3 certificate they do not even know how to shower a person, how to wash them properly, how to toilet them properly or how to transfer them properly. Yet these people are being put into aged care to look after elderly people. There needs to be some sort of training outside before you enter them into aged care.⁷¹

2.60 The Aged Care Lobby voiced similar concerns:

When you look at the personal carers it is easy to see why care is not what it should be. Personal carers can go to do a TAFE course with year 10 qualifications. They have a 16-week course – seven weeks of lectures and nine weeks of practical work – and they have to have a mature St John Ambulance certificate at the end of the course. Is that adequate to provide someone with the skills to look after elderly people...I suggest to you that that is the problem in most aged care facilities: looking at the prerequisites that are needed to look after elderly people.⁷²

The HSU commented that the Commonwealth should 'move as quickly as possible to put in place a requirement for all new staff entering the industry to be qualified to an aged care certificate III standard'.⁷³

69 Senate Community Affairs Legislation Committee, *Estimates*, 2.6.04, p.CA135 (DoHA).

70 *Committee Hansard* 26.4.05, p.47 (HSU).

71 *Committee Hansard* 26.4.05, p.54 (HSU).

72 *Committee Hansard* 22.2.05, p.30 (Aged Care Lobby).

73 *Submission* 122, p.17 (HSU); see also *Submissions* 71, p.4 (RCNA); 74, p.6 (ANHECA).

2.61 In relation to helping care workers to upgrade to enrolled nurses, the Queensland Government supported this initiative as it offers a career pathway for unregulated workers into nursing and stated 'the backbone of both the residential and community care workforces is 'unregulated' workers'. Their access to pre and post employment training to Certificate III and beyond was seen as a key issue that needs to be tackled as part of a national strategy.⁷⁴

2.62 Similarly, the ANF welcomed the funding initiative but advocated that the funding be provided to registered training providers to enable them to offer additional enrolled nursing courses. The ANF noted however that obtaining the quality clinical placements essential to the enrolled nursing qualification may present a significant difficulty. The ANF went on to comment that it was concerned with the growing number of personal carers accessing a Certificate IV qualification that does not lead to licensing as an enrolled nurse. It stated that 'the licensing of people providing nursing care is an important process that provides protection and recourse for the public whose lives depend on those who are caring for them'.⁷⁵

2.63 Geriaction stated that care workers often seek access to enrolled nurse training. However places to do so are short and if they do access a place 'they have to leave their current workplace, go to an acute care environment and work rotating rosters, which is not consistent with family and other work issues'. Geriaction concluded that:

There are some real barriers to access to those courses...I think there is a need to look at the whole notion of teaching centres for aged care where we develop centres of excellence, have training from multidisciplinary people and develop relationships with universities...They engender the culture of learning and research which is critical to keeping people in the discipline and in the specialty itself.⁷⁶

2.64 The Tasmanian Government commented that, while the 2004-05 Budget included measures for aged care education and training, it is understood that education and training for workers in the residential aged care will be paid direct to aged care providers to fund training for enrolled nursing. Funding through normal VET system channels is preferred as it would enable better strategic targeting of training to meet industry needs.⁷⁷ The HSU also called for greater accountability mechanisms to be built into payments for providers to ensure an agreed level of workforce training is provided in each aged care facility.⁷⁸

74 *Submission 193*, p.7 (Queensland Government); see also *Submission 173*, p.2 (ACS Australia).

75 *Submission 201*, p.20 (ANF).

76 *Committee Hansard 19.8.04*, p.43 (Geriaction).

77 *Submission 200*, p.2 (Tasmanian Government).

78 *Submission 122*, p.18 (HSU).

2.65 The Queensland Government commented on pathways for enrolled nurses to continue into registered nursing and other health professions. It stated that 'for this to occur there would need to be incentives for universities to offer articulation pathways which do not require unnecessary duplication of previous training or unreasonably extend the number of years students need to study'.⁷⁹

2.66 During the Committee's 2002 inquiry into nursing, witnesses commented on articulation. The ANF argued that formal articulation and recognition of prior learning arrangements should be developed between Certificate III courses for unlicensed nursing and personal care assistants (however titled) and enrolled nurse courses. It was also stated that a possible pathway could include the opportunity for students to enter as personal care assistants through the TAFE sector. These students would then be offered the opportunity to progress into an EN program and from then to a Licensed Practical Nurse program (based on the US model where these nurses have a specific role which is different from that of the RN), and then onto completion of the program as a RN. The Committee recommended that formal articulation arrangements and recognition of prior learning be developed between Certificate III courses for unregulated healthcare workers and enrolled nurse courses, and between courses for Aboriginal and Torres Strait Islander health workers and enrolled nurse courses.⁸⁰

Enrolled nurse medication management training

2.67 Enrolled nurses are able to administer certain medication but must receive the relevant training. VAHEC stated that this training cost approximately \$3,000 per person and precluded some enrolled nurses and providers from accessing training.⁸¹

2.68 The Commonwealth's initiative aims to assist 5 250 enrolled nurses to access training to allow them to administer medication. This initiative was seen as overcoming a barrier to medication training and as a positive step in improving the skills base of the aged care workforce. The funding would ensure medication management was not relegated to a category of worker with no pharmacology education. Medication management by enrolled nurses would also allow more effective utilisation of registered nurses and allow 'sensible and rational work practices to evolve based upon the capabilities of the various categories of staff'.⁸² It was also hoped that this measure will enhance the enrolled nurse role and lead to more enrolled nurses remaining in aged care.⁸³

2.69 However, witnesses questioned whether the funding would be adequate. They pointed to the Hogan Review's recommendation that the Commonwealth should

79 *Submission 193*, p.7 (Queensland Government).

80 *The Patient Profession*, pp.80-81.

81 *Submission 150*, p.5 (VAHEC).

82 *Submission 74*, p.6 (ANHECA).

83 *Submission 71*, p.4 (RCNA).

support aged care providers to assist at least 12 000 enrolled nurses to complete medication management training by 2007-08.⁸⁴ The Queensland Government stated that:

The Commonwealth Government's initiatives in promoting an aged care workforce capable of meeting contemporary and future challenges, while important and useful, operate in the absence of a clear strategic context. Thus while initiatives directed to improving the medication management skills of enrolled nurses are 'a positive', it is not known whether the numbers of positions targeted have been based on the best available evidence of projected need.⁸⁵

Wage parity

We do not believe that the recent budget initiatives go far enough in addressing wage parity issues. We are concerned that if we do not actually address that problem it will ultimately impact – if it has not already – on the actual quality of care being provided to people in residential care.⁸⁶

No amount of education and training support will make up for the lack of funding to provide comparative wages with the acute sector.⁸⁷

2.70 Wage disparity between the aged care sector and other areas of nursing was seen as a major impediment to recruitment and retention in the aged care workforce. As noted above, wage disparity occurs in all jurisdictions. There is disparity between the aged care sector and other health sectors, between government and non-government facilities and at all workforce levels in the aged care sector.

2.71 The Commonwealth's additional funding aimed to help providers increase wages was made in two parts: in the 2002-03 Budget, funding over four years for subsidy increases was provided; and in 2004-05 funding over four years for conditional adjustment payment was provided.

2.72 Witnesses argued that the Commonwealth's additional funding had failed to close the gap between wages in the aged care sector and other health sectors. Two reasons were advanced for the failure of this initiative. First, it was argued that the funding was not being directed towards wages as there was no mechanism for ensuring that this in fact occurred. Secondly, that the additional funding was insufficient to close the gap.

2.73 Without a mechanism to ensure that the funding went to addressing the disparity in wages, nurses feared that the money would not be used as intended but

84 See for example, *Submission 150*, p.6 (VAHEC).

85 *Submission 193*, p.4 (Queensland Government).

86 *Committee Hansard 19.8.04*, p.34 (Geriaction).

87 *Submission 89*, p.1 (Nurses Board of Western Australia).

'instead end up in the consolidated revenue of aged care facilities'.⁸⁸ The NSW Nurses Association stated:

Without extra conditions on the \$877.8 million incentive payment to mandate that service providers use the money to improve wages and conditions, the NSW Nurses Association does not have any expectation that the employment conditions for nurses in aged care will improve. It will not make any difference in this budget, as it made no difference in previous budgets. Until there is quarantined funding for nurses wages, it is unlikely that service providers will pass on any extra funds.⁸⁹

2.74 The HSU also noted that there is a significant wage gap of \$60 to \$70 a week for carers between the public sector and the aged care sector. The HSU stated that carers in public hospitals do far less than carers in aged care.⁹⁰ HSU (NSW) voiced concerns on behalf of its members that the conditional adjustment payment would not be used to improve wages:

But I am not confident that they will respond in that manner. I am not confident that they see that money as going towards staffing and salaries and I do not believe there is anything in the budgetary measures that actually locks them in and requires them to spend that money on staffing or salaries. That is our concern.⁹¹

2.75 The ANF considered that the amounts provided in the Budget provision were sufficient to achieve parity but were not being used to do so:

The amounts that the government allocates are sufficient to achieve parity. Both in the \$877.8 million and previously in the \$211 million, the amounts were sufficient. It is just that they do not get to wages because there is no mechanism or no requirement that they do so.⁹²

The ANF argued that the providers 'were quite deliberately depressing wages because it is a good reason to put pressure on the government to give them more money'.⁹³ Witnesses recommended that a mechanism be put in place that ensured that the additional funding provided by the Commonwealth was directed at wages.⁹⁴

2.76 As part of the eligibility requirements for the conditional adjustment, providers are required to encourage staff to undertake training, publish audited financial statements and participate in periodic workforce surveys. The ANF indicated

88 *Submission* 71, p.3 (RCNA).

89 *Submission* 179, p.3 (NSW Nurses Association).

90 *Committee Hansard* 26.4.05, p.44 (HSU).

91 *Committee Hansard* 19.8.04, p.73 (HSU NSW).

92 *Committee Hansard* 11.2.05, 37 (ANF).

93 *Committee Hansard* 11.2.05, p.45 (ANF).

94 See for example, *Submissions* 186, p.5 (QNU); 201, p. 19 (ANF); *Committee Hansard* 19.8.04, p.63 (HSU NSW).

there were some difficulties with providing audited statements in that some entities are part of a larger entity 'which means it is impossible to differentiate'. The ANF stated that a working group was 'trying to develop a format for what that reporting means and what will actually be reported'. While it was hoped that would enable the allocation of funds to be identified 'at the moment we do not have – and have not had since 1997 – any way of telling how much providers are spending on particular things, and the audited accounts do not give that detail at all'.⁹⁵

2.77 Other witnesses argued that wage disparity would not only continue but would increase as the additional funding was insufficient to close the gap. The Tasmanian Government commented:

The Commonwealth Budget provided a welcome increase in the subsidies paid for residential aged care, with a supplement of 1.75 per cent being added annually for the next four years. However, this will generally not be sufficient to enable aged care employers to pay wages that are competitive with the public hospital sector. Linking aged care subsidies to an appropriate index of health sector wages would achieve this, or alternatively, increasing the supplementary payment. Until pay parity is achieved it will remain very difficult for the current workforce issues in residential aged care to be effectively addressed.⁹⁶

2.78 CHA stated that its modelling of the conditional adjustment payment would mean that there would still be a shortfall of around \$170 a week for a nurse working in an aged care facility as compared to a hospital. CHA commented that 'because the aged care program is so heavily reliant on government subsidy around the care funding, which goes to wages, and because the overall operating budget is so significantly determined by wages, the gap unfortunately is exacerbated'.⁹⁷

2.79 UnitingCare stated that the current indexation system resulted in inaccurate costing of wages in the sector. It gave the example of one of its providers in Queensland which faced wage rises of approximately 6 per cent per year over the last three years, while indexation had been closer to 2.5 per cent.⁹⁸

2.80 UnitingCare also noted that the 2004 Budget allocation of \$877.8 million over four years meant that the Commonwealth had agreed to indexation totalling 3.76 per cent (1.75 per cent for the adjustment and 2.01 per cent indexation) in the current financial year. UnitingCare concluded that, while the increase in funding is welcome, 'the figures strongly suggest the scope of the increase is not large enough to keep pace with annual cost increases and:

95 *Committee Hansard* 11.2.05, p.37 (ANF).

96 *Submission* 200, p.2 (Tasmanian Government).

97 *Committee Hansard* 11.2.05, p.9 (CHA).

98 *Submission* 57, p.5 (UnitingCare).

The increase will certainly not provide sufficient funding to redress the existing disparity of wages between the aged care and public hospital sectors. The aged care sector is reaching the end of its capacity to absorb the disparity between funding and expenditure.⁹⁹

2.81 The Aged and Community Services Association of NSW & ACT also agreed that although the increased residential aged care subsidies would 'go some way to alleviating the pressure for providers, it will generally not be sufficient to enable aged care employers to pay wages that are competitive with the public hospital sector'. The Association stated that actual wage costs were rising faster than aged care subsidies. The formula for the annual indexation of subsidies included only the amount of the safety net wage adjustment. Industry pay rates have increased by significantly more than the subsidy rates, driven in large part by wage settlements in the public hospital sector. In addition, the Association argued that setting of a national rate for the subsidy, did not take into account differences in wage rates between jurisdictions. For example, nurse wages in NSW are 12 per cent more than in any other jurisdiction.¹⁰⁰

Community care

2.82 As noted above, the aged care community workforce has grown rapidly in response to changes in policy direction. Witnesses commented that the Commonwealth's initiatives tend to address residential aged care workforce issues only. The Tasmanian Government commented that the initiatives were inconsistent with the direction of government policy as programs emphasised people remaining in their homes as long as possible and the focus is on training funding in residential care.¹⁰¹ CHA believed that:

...there would be greater merit in bringing together the strategic workforce issues affecting all aspects of aged care. This would provide a more comprehensive and coordinated response which would address residential and community care together with geriatric care in the acute sector.¹⁰²

Workforce planning and the National Aged Care Workforce Strategy

2.83 While there was support for the Commonwealth's initiatives, they were seen as only addressing part of the problems facing the aged care sector. The Tasmanian Government stated that while these initiatives are useful in their own right, they tend to focus on the residential aged care workforce and neglect strategic issues confronting the aged care sector as a whole. Community care workforce issues, in

99 *Submission 57*, p.6 (UnitingCare).

100 *Submission 170*, p.6; *Committee Hansard* 19.4.04, p.23 (ACS Association of NSW & ACT). See also *Committee Hansard* 18.3.05 p.16 (Aged Care Qld).

101 *Submission 200*, p.3 (Tasmanian Government); see also *Submissions* 13, p.2 (Inner West 5 Home and Community Care Forum); 193, p.7 (Queensland Government).

102 *Submission 166*, p.4 (CHA).

particular, merit further attention.¹⁰³ Geriaction saw the initiatives as 'bandaid measures', which failed to address the need for a comprehensive workforce planning strategy.

2.84 The need for a long term and national approach to workforce planning was supported by other evidence.¹⁰⁴ For example, the Queensland Government commented that there is a case for the development and implementation of a coherent national workforce plan to deal with immediate and medium term workforce challenges. In doing so, the Queensland Government stated that the Commonwealth and State and Territory Governments will need to work closely in partnership with professional associations and education/training providers in the development of a national approach. The Government noted that the Council of Australian Governments (COAG) recently agreed to the development of a health workforce plan and stated that work on an aged care workforce plan could usefully occur in tandem with this work.¹⁰⁵

2.85 NSW Health also argued that greater collaboration between all parties involved in the training of our health workforce is critical to ensure it is truly patient focused. It considered that a team-based approach to learning, across and within professions, needs to be fostered in the education sector and reinforced in the workplace. This is particularly important in care of the aged where coordination of professional effort can result in significantly improved health outcomes.¹⁰⁶

2.86 NCOSS stated that commented, in relation to community care:

...we all know of the shortages that are emerging in aged and community care services and the desperate need – beyond perhaps some of the shorter-term measures that have been taken in recent times by governments at the Commonwealth and state levels – to have a much longer-term approach to work force development dealing with skill shortages and looking at the growth areas within these industries, broadly speaking.¹⁰⁷

2.87 In April 2005, the Minister for Ageing launched the *National Aged Care Workforce Strategy*. In doing so the Minister stated that:

There are strategies to deal with workforce supply, education and training, recruitment and retention issues, the image of aged care, so that we can promote aged care across all age sectors, as a career of choice...[it] will take this sector forward, and add much to the maturity of the aged care

103 *Submission* 200, p.2 (Tasmanian Government).

104 *Submissions* 125, p.2 (Aged & Community Care Services SA & NT);

105 *Submission* 193, p.4 (Queensland Government).

106 *Submission* 202, p.9 (NSW Health).

107 *Committee Hansard* 11.3.05, p.47 (NCOSS).

sector, and our ability to attract and retain and reward aged care professionals.¹⁰⁸

2.88 Although the Strategy was launched toward the end of the Committee's inquiry, some witnesses provided comments. Both VAHEC and ACS Australia welcomed the Strategy, but suggested that its scope should be extended to include community care. ACS Australia indicated that it had raised the matter with DoHA and 'that is something that they now support, perhaps for the next iteration of the strategy, which is a welcome development from our point of view'.¹⁰⁹

2.89 The AMA stated it was disappointed that the Strategy and the National Aged Care Workforce Census did not consider medical practitioners to be part of the aged care workforce. The AMA commented 'general practitioners are the backbone of the health service in this country, yet GP participation in residential aged care facilities has declined'.¹¹⁰

2.90 The Australian Physiotherapy Association also commented that the Strategy had not addressed its important place in the aged care sector:

We struggled to get the very important role of physiotherapy in the aged care sector recognised in the way that it should be...the remit that they had been given by the government or by the department did not allow them to include those comments. During those meetings I had terrific support from the other health professionals who were there as to the importance of physiotherapy in the sector, but we faced this blank refusal to acknowledge that physiotherapists are a core component of the aged care workforce. There seemed to be no logic, and there was no reason or rationale offered; it was simply stated that this was the limit of the study and that was all that would be examined.¹¹¹

2.91 VAHEC raised the issue of funding and the need for cooperation:

There are also issues, once again, about who will pay for this. It also emphasises the cooperation that will be needed between both levels of government, particularly with regard to the state government addressing some of the barriers we currently experience in recruiting and retaining staff.¹¹²

2.92 HSU was particularly critical, noting that there was little detail and did not address significant issues:

108 The Hon J Bishop, Minister for Ageing, *Address to the Australian Nursing Home and Extended Care Association Nursing and Management Congress*, Sydney, 21 April 2005.

109 *Committee Hansard* 26.4.05, p.1 (ACS Australia).

110 *Committee Hansard* 11.2.05, p.21 (AMA).

111 *Committee Hansard* 27.4.05 p.61 (APA).

112 *Committee Hansard* 26.4.05 pp.3-4 (VAHEC).

Without trying to be too critical, having read through that document I could not understand one thing that it was actually proposing in a concrete sense. It appeared to me to be incredibly general. It did not address any of the issues that we have tried to bring to the Senate's attention today and in our submissions. We ask: how can you ever have some sort of workforce planning document that does not come to terms with the very basic question of how many staff you need to adequately look after people in an aged care facility? That document certainly did not do that at all.¹¹³

The lack of concrete indication of need was echoed by the Mary Ogilvy Homes which stated 'in this document there does not seem to have been any formal sort of gap analysis'.¹¹⁴ The HSU concluded that it was 'a lost opportunity' and that:

We do not even see it as a good step in the first direction, because we do not see that it has set any direction at all in that particular document. We are very critical of the lost opportunity that could have been taken by the committee in that particular document.¹¹⁵

Conclusion

2.93 In its conclusion on aged care workforce issues, the Committee can but reiterate what has been said many times before: that the shortage of nurses is real, is increasing and is impacting on the quality of care being delivered in all health sectors but more particularly in the aged care sector. The shortage of nurses will continue and become more severe as the impact of an ageing workforce is felt and if the number of graduates is insufficient to replace those retiring. Shortages of medical practitioners and allied health professionals in the aged care sector are also evident. The shortages in all professions across the sector will increase as demand for a skilled aged care workforce increases as the general population ages.

2.94 The Committee acknowledges that the Commonwealth and the State and Territory Governments have instituted programs and initiatives to address the shortages. However, the evidence continues to indicate that more needs to be done. There is a need for greater coordination of workforce planning and greater coordination between governments and the tertiary sector. In relation to aged care nursing, the Committee considers that the Commonwealth should re-examine the recommendations of the Hogan Review on the number of undergraduate nursing places required with a focus on aged care. However, the Committee is mindful that there is still a need to improve the image of the aged care sector, and more particularly to reach pay parity to encourage new graduates to remain in aged care nursing. Without this, the Government's efforts to increase the aged care workforce will be ineffective.

113 *Committee Hansard* 26.4.05, p.50 (HSU).

114 *Committee Hansard* 28.4.05 p.28 (Mary Ogilvy Homes Society).

115 *Committee Hansard* 26.4.05, p.50 (HSU).

2.95 The *National Aged Care Workforce Strategy* has been launched in an effort to address the needs of the aged care workforce. While a welcome first step, the Committee is disappointed that after so many years of reports and reviews, the Strategy is limited in scope as it is directed at residential aged care and does not encompass all areas of the aged care workforce. The Committee finds this a particularly disappointing aspect of the Strategy given the Commonwealth's policies aimed at keeping older people in their homes for as long as possible. The Strategy also does not include all professions engaged in the aged care sector. While it is noted in the introduction to the Strategy that work will be needed to broaden the strategic response to cover the full aged care workforce in all settings, the Committee considers that the limited focus of the Strategy is yet another example of where a great deal of work has failed to provide a comprehensive, cohesive and coordinated approach to a significant problem. It is not that residential care is the only area where there are workforce shortages, all areas face difficulties. Strategies to increase the number of skilled workers, be they nurses or other health professions, will take a number of years to impact. In the interim, the significant workforce difficulties in the sector may remain.

2.96 More importantly, the Strategy does not identify who will take a leadership role to ensure that the strategies are progressed and implemented. While there are areas of responsibility without commitment and leadership at the highest levels by all governments, the Committee is concerned that the Strategy will fail to deliver much needed reforms in the aged care sector.

Recommendation 1

2.97 The Committee welcomes the Commonwealth's allocation of 400 extra nursing places at universities in the 2004-05 Budget. However, the Committee recommends that the Commonwealth further increase the number of undergraduate nursing places at Australian universities to 1000 as recommended by the Hogan Review.

Recommendation 2

2.98 That the Commonwealth work with aged care providers to ensure that their shared responsibility to assist enrolled nurses to complete medication management training meets the target as recommended by the Hogan Review.

Recommendation 3

2.99 That the Commonwealth implement a strategy which allocates an appropriate number of undergraduate nursing places on the basis that recruitment for those places occurs from the current residential and community care workforce in both rural and urban settings proportionally.

Recommendation 4

2.100 That the Commonwealth investigate the effectiveness of incentives for staff to work in aged care settings in rural and remote areas.

Recommendation 5

2.101 That the Commonwealth, as a matter of priority, expand the National Aged Care Workforce Strategy to encompass the full aged care workforce, including medical and allied health professionals, and all areas of the aged care sector, in particular the community care sector.

Recommendation 6

2.102 That the Department of Health and Ageing and the Department of Education, Science and Training, as part of the National Aged Workforce Strategy, ensure the inclusion of quality aged care curricula in undergraduate nursing.

Recommendation 7

2.103 That the Commonwealth consider implementing mechanisms to ensure that the conditional adjustment payment aimed at restoring wage parity for nurses, personal carers and other staff in the aged care workforce is used to meet this aim.

CHAPTER 3

THE AGED CARE STANDARDS AND ACCREDITATION AGENCY

3.1 This chapter discusses the performance and effectiveness of the Aged Care Standards and Accreditation Agency (the Agency) in terms of:

- assessing and monitoring care, health and safety of residents in aged care facilities;
- identifying best practice and providing information, education and training to aged care facilities; and
- implementing and monitoring accreditation in a manner which reduces the administrative and paperwork demands on staff.

3.2 The Agency plays an important role in the regulation of the aged care industry. Evidence to the inquiry strongly emphasised that an effective regulatory regime is important to protect elderly people placed in aged care facilities – people who represent some of most vulnerable, frail, and dependent members of the community. The regulator also has an important role in ensuring accountability of the sector – a sector that receives very considerably public monies to provide aged care services.

Role of the Aged Care Standards and Accreditation Agency

3.3 The Agency is an independent company established by the Commonwealth Government under the *Aged Care Act 1997*, is limited by guarantee incorporated under the *Corporations Act 2001* and is subject to the *Commonwealth Authorities and Companies Act 1997*. The Agency was appointed as the 'accreditation body' for residential care services and the *Accreditation Grant Principles 1999*, made in accordance with the Aged Care Act, specify the functions of the accreditation body and the procedures it is to follow in carrying out those functions.

3.4 The core functions of the Agency include:

- managing the accreditation process using the Accreditation Standards;
- promoting high quality care, and assisting the industry to improve service quality, by identifying best practice and providing information, education, and training to industry;
- assessing and strategically managing services working towards accreditation; and
- liaising with the Department of Health and Ageing (DoHA) about services that do not comply with the Residential Care Standards or the Accreditation Standards.

3.5 Operationally these functions translate into activities that can be described as:

- assessing homes for compliance with the Accreditation Standards and determining the period of accreditation; and
- promoting high quality care and helping homes improve service quality by providing education and information.

3.6 The Agency works within the broader regulatory framework that governs the funding and provision of residential aged care. The framework includes the Aged Care Act, the various Aged Care Principles, the Complaints Resolution Scheme and State and local government legislation.¹

Assessing and monitoring care, health and safety

3.7 The Agency assesses compliance of residential aged care services against the Accreditation Standards made under the *Quality of Care Principles 1997* that consist of four parts involving:

- management systems, staffing and organisational development – 9 expected outcomes;
- health and personal care – 17 expected outcomes;
- resident lifestyle – 10 expected outcomes; and
- physical environment and safe systems – 8 expected outcomes.

3.8 The Standards specify the outcomes that are to be achieved for residents but they do not prescribe how the home must achieve the outcome. This approach provides the opportunity for providers to tailor care and services in a way that best meets the residents' needs and expectations.

3.9 The accreditation process involves a team of at least two registered aged care quality assessors evaluating all aspects of a home's performance through an assessment of the accreditation application and a two to three day site audit. The site audit includes interviews with residents, their families, staff and management. The assessment team will examine relevant documentation, and observe the living environment and practices of the home. Information is gathered to analyse the home's performance against the 44 outcomes.

3.10 There were 2949 accredited homes as at 30 June 2004 – 2640 homes (or 90 per cent) were accredited for three years, 78 (3 per cent) for between two and three years, and 225 (8 per cent) for two years or less. Some 6 homes have accreditation for four years.²

1 *Submissions* 105, pp.2-5 (ACSAA); 191, pp.27-30 (DoHA).

2 The Aged Care Standards and Accreditation Agency, *Annual Report 2003-04*, p.17.

3.11 The Agency also monitors the performance of all accredited homes to ensure quality care is provided to residents in accordance with the Accreditation Standards. Visits to homes to monitor their performance may be 'support contacts' or 'review audits'. The Agency also conducts some of its visits at short notice ('spot checks').

3.12 All accredited aged care homes are subject to a regular series of support contacts conducted by the Agency, the purpose of which is to monitor a home's ongoing compliance with the Accreditation Standards and the Aged Care Act. A support contact involves either a visit to the home or a telephone contact, conducted by quality assessors. A support contact (site) generally lasts from half to one-day and may involve an overview of the home's performance against all the Accreditation Standards, or may be focussed on certain aspects of care or services. A support contact (desk) is a one or two hour teleconference between a quality assessor and the management of the home. In 2003-04, 2904 support contacts were undertaken, of which 2815 were site visits and 89 were phone contacts.³

3.13 Review audits assess the quality of care provided by a home against the expected outcomes of the Accreditation Standards. Review audits may be conducted if the Agency has reason to believe a home is not complying with the Accreditation Standards; there has been a change to the home such as a change of ownership or key personnel; or the home has not complied with the arrangements made for support contacts. In 2003-04, 86 review audits were conducted, and 82 decisions were made following the review audits. Of these decisions, 44 were to vary the period of accreditation, 36 were to not vary accreditation and two were to revoke accreditation.⁴

3.14 The Agency also conducts random and targeted spot checks. They can either be support contacts or review audits. A spot check is a visit where homes are given less than 30 minutes notice. Approximately 15 per cent (553) of all Agency site visits in 2003-04 were conducted as spot checks.

3.15 Under the Deed of Funding with DoHA, which commenced in July 2004, the Agency is required to visit each home at least once a year and maintain an average visiting schedule of 1.25 visits per home per annum. These visits may either be a site support contact or review audit (and may also be conducted as spot checks). Additional visits are arranged where the Agency assesses that there is a need for more visits such as a reason for concern or serious risk has been identified.⁵

Views on quality of care

3.16 Evidence to the inquiry expressed a range of views on the impact of accreditation on the quality of care in aged care facilities. Aged care providers, in particular, suggested that since the introduction of accreditation the overall quality of

3 Annual Report, p.19.

4 Annual Report, p.20.

5 *Submission* 105, Supplementary Information, 27.5.05 (ACSAA).

care standards has improved across the industry. The Australian Nursing Homes & Extended Care Association (ANHECA) noted that:

...the introduction of the accreditation system has had a profound effect upon residential aged care and has driven a significant improvement in the quality of services, but more particularly, led to the adoption within residential care services of the systemisation of quality improvement systems within organisations leading to services incorporating these systems within their day to day service delivery framework.⁶

3.17 Catholic Health Australia (CHA) also recognised a lift in overall quality of care standards across the industry as a whole, while the Review of Pricing Arrangements in Residential Aged Care (Hogan Review) noted that 'submissions and evidence presented at consultations indicate broad support for accreditation. There is general acknowledgment that standards of care and accommodation across the industry have been improved substantially by accreditation'.⁷

3.18 Other submissions have, however, raised concerns about the standards of care across the industry. The Health Services Union (HSU) noted argued that the Agency 'is failing in its duty to ensure that an adequate standard of care and safety is provided to elderly residents in aged care facilities'.⁸ The Australian Nursing Federation (ANF) also noted that many of its members have raised issues about inadequate standards of care and inadequate staffing levels in aged care facilities.⁹

3.19 Seniors groups raised similar concerns. COTA National Seniors expressed concerns as to the extent to which accreditation has contributed to high quality care for residents and real options about lifestyle for residents.¹⁰ The Combined Pensioners & Superannuants Association of NSW (CPSA) stated that the performance of the agency 'leaves much to be desired'. The Association argued that part of the problem is that the Agency is not set up to directly control aged care facilities. The accreditation system gives substantial power to proprietors – 'they are allowed considerable leeway in terms of how services are carried out'.¹¹ The Association argued that the Agency should be abolished and aged care brought under the direct control of DoHA.

3.20 Evidence indicates that there is little systematic data that demonstrates how accreditation has impacted on quality of care. One submission noted that the Agency has 'not produced any material which would provide the sector or the community with

6 *Submission 74*, p.8 (ANHECA).

7 *Submission 166*, p.6 (CHA); Hogan WP, *Review of Pricing Arrangements in Residential Aged Care, Final Report*, Canberra, 2004, p.239.

8 *Submission 122*, p.18 (HSU).

9 *Submission 201*, p.10 (ANF). See also *Committee Hansard 27.4.05*, pp.47-50 (ANF).

10 *Submission 174*, p.8 (COTA National Seniors).

11 *Submission 79*, p.5 (CPSA).

any level of assurance that the overall intention of accreditation in improving service quality has been achieved'.¹²

3.21 The Audit Office also raised this as an issue in a recent audit report. It recommended that the Agency and DoHA plan an evaluation of the impact of accreditation on the quality of care in the residential care industry.¹³ This recommendation was accepted by both the Agency and the Department and the project is expected to be completed in 2006.

3.22 While anecdotally it appears that quality of care has improved in aged care facilities since the introduction of accreditation, a number of concerns were raised in evidence and these are discussed below.

Ensuring adequate standards of care

Improved accreditation processes

3.23 Evidence indicates that there is a need for improvements in accreditation processes.

3.24 A number of criticisms of the Agency by providers and their peak bodies were raised especially relating to the first round of accreditation. The criticisms centered on inconsistencies between assessors' approaches, problems with duplication in the Accreditation Kit, inaccurate comments appearing in final reports, lack of process to correct mistakes and inconsistency where some decisions were overturned and other seemingly similar decisions were not.¹⁴

3.25 Comments from providers during the inquiry generally indicated that many of these problems were addressed in the second round of accreditation. CHA noted that due to the more rigorous requirement in round two for assessors to have evidence of non-compliance, member services found that the process was fairer and more balanced.¹⁵ Aged and Community Services (ACS) SA & NT also reported that while their members were initially critical of the Agency and its processes a more recent survey of members indicated 'overwhelming support for the agency and the accreditation process'.¹⁶

3.26 A number of current issues of concern were, however, raised during the inquiry and these are discussed below.

12 *Submission 74*, p.8 (ANHECA).

13 ANAO, *Managing Residential Aged Care Accreditation*, Audit Report No. 42, 2002-2003, pp.19,82.

14 *Submission 170*, p.9 (ACS of NSW & ACT).

15 *Submission 166*, p.6 (CHA).

16 *Committee Hansard 22.2.05*, p.3 (ACS SA & NT).

Lack of consistency in assessments

3.27 Aged care providers, provider peak bodies and others complained of the lack of consistency in the assessments made by different assessors. Blue Care noted that:

...[there are] inconsistencies in the understanding and knowledge of different auditors when applying the standards to an aged care facility. It is important that there is a consistent approach to assessing and monitoring the health and safety among auditors.¹⁷

3.28 The HSU stated that 'even the most casual analysis of the publicly available reports produced by the agency shows huge inconsistencies in the level of scrutiny applied by agency inspectors and in the reports they produce'. The HSU reported that many of its members expressed concerns regarding the way accreditation visits are carried out and the level of scrutiny applied by inspectors.¹⁸

3.29 Submissions noted that a facility may achieve 44 satisfactory outcomes during accreditation and be accredited for 3 years. Within months a support visit may find that the facility is non-compliant with one or more outcomes. A finding of this nature can be difficult to explain and demonstrates an unacceptable level of subjectivity in the process.¹⁹

3.30 CHA noted that the main reason for the lack of consistency is the Agency's approach focuses primarily on examining the systems and processes that facilities have in place to demonstrate that they meet each of the expected outcomes – 'as these outcomes are expressed in generalised terms, assessment of compliance must, as a requisite, involve subjective elements of judgement'.²⁰ The HSU commented that the vague nature of the Accreditation Standards and the lack of guidelines contributes to the problem as is the use of less qualified contract staff by the Agency at times of peak demand.²¹

3.31 Submissions also argued that training of assessors needs to be improved. The CPSA argued that the training courses for assessors are inadequate – 'QSA's training courses for aged care assessors run for 5 days and appear to have no pre-requisites apart from a willingness to learn. The courses are presumably of a high standard but 5 days does seem too short to guarantee assessors will be trained to make appropriate assessments of aged care facilities' standards'.²²

17 *Submission* 116, p.3 (Blue Care). See also *Submission* 162, p.3 (Baptistcare).

18 *Submission* 122, pp.19-20 (HSU).

19 *Submissions* 170, p.9 (ACS of NSW & ACT); 166, p.6 (CHA). See also *Committee Hansard* 22.2.05, p.3 (ACS SA & NT).

20 *Submission* 166, p.6 (CHA).

21 *Submission* 122, p.19 (HSU).

22 *Submission* 79, p.7 (CPSA).

3.32 Regarding the qualification of assessors, the Agency conceded that there is no formal qualification requirements prior to selection however, they stated that only persons who are registered aged care assessors are permitted to conduct assessments. There are 362 registered aged care quality assessors registered by the Quality Society of Australasia. Some 65 of those assessors are currently permanent employees of the Agency. Over half of them are registered nurses (RNs) and about 80 per cent have post-secondary qualifications other than registered aged care assessor qualifications. Additional contractors are used to supplement the permanent assessors, especially during peak times. Assessors are required to successfully complete a training course on aged care quality assessment and complete an orientation program.²³

3.33 ANHECA submitted that the Agency also needs to provide more data analysing the effectiveness of assessors in their auditing role. The Association noted that the Agency needs to 'apply resources to the development of a substantially improved data mining and reporting capacity, which would have the capacity to report on assessors and audit outcomes at an individual, regional, state and national level'.²⁴ UnitingCare Australia suggested that more consistency may require the use of benchmarking or external auditors.²⁵

3.34 The Agency noted that it is reviewing and further developing its quality assurance measures, including:

- reviewing arrangements for the registration of quality assessors including improved competency specifications, and revised training and assessment program;
- introduction of internal and independent reviews of samples of accreditation decisions and audit reports to evaluate their conformity with Agency standards; and
- organisational restructuring including the creation of Principal Assessor and Assessment Manager positions in each State office.²⁶

Conclusion

3.35 The Committee believes that the Agency should ensure that there is a consistent approach by assessors at all times in conducting assessments. The Committee notes that the Agency is reviewing and further developing its quality assurance measures and believes that these initiatives should continue.

3.36 The Committee also considers that the Agency should establish benchmarks against which assessors' decisions can be evaluated and that this information should

23 *Submission 105*, p.8 (ACSAA); *Committee Hansard 19.8.04*, pp.83,96-97 (ACSAA).

24 *Submission 74*, p.8 (ANHECA).

25 *Submission 57*, p.7 (UnitingCare Australia).

26 Annual Report, pp.20-21.

be published annually. The Committee also believes that a significant reason for the lack of consistency relates to interpretation of the Accreditation Standards which are expressed in very generalised terms and therefore open to markedly different interpretations. The Committee has made recommendations later in this chapter addressing this issue.

Recommendation 8

3.37 That the Agency ensure that the training of quality assessors delivers consistency in Agency assessments of aged care facilities.

Recommendation 9

3.38 That the Agency publish data on the accuracy of assessors' decisions in conducting assessments against Agency benchmarks and that this data be provided in the Agency's annual report and on its website.

'Enhancement' of facilities prior to accreditation visits

3.39 Some submissions argued that accreditation processes encouraged some homes to employ additional staff and generally 'tidy up' the facility prior to the arrival of assessors which created a false impression of the true nature of the facility and the services provided.

3.40 The HSU noted that:

Scheduled accreditation gives management the opportunity to roster extra staff on, adjust menus and activities, and generally have everything looking ship shape for the accreditors. However, members argue that the standards shown off at accreditation are rarely maintained outside of accreditation periods.²⁷

3.41 The NSW Nurses' Association also noted that members routinely reported that 'the accreditation process is a farce as everything is set up for the day and then disappears'.²⁸ The Nurses Board of WA similarly commented that:

Arriving as anyone would arrive to an institution, you do get a feel of what normally happens. With the provision of notice, there is opportunity for preparation that may not normally be done.²⁹

3.42 The Agency countered these claims stating that it receives information from time to time about homes attempting to mislead assessors about their compliance with the Standards by increasing staff and doing other things before a visit – 'however in

27 *Submission 59*, p.12 (HSU - NSW Branch).

28 *Submission 179*, p.6 (NSWNA).

29 *Committee Hansard 23.2.05*, p.17 (Nurses Board of WA).

these few cases, our follow up has failed to find evidence that supports the claims made to us'.³⁰

3.43 The Agency advised that:

Accreditation is not a one-off event...Assessors triangulate evidence of homes meeting the expected outcomes by interviewing residents and staff, reviewing the systems, policy and processes documentation and other records such as care plans, staff rosters and menus etc.³¹

3.44 The Committee is concerned, however, that the evidence received suggests that some homes may engage in the practices described above. It notes that complaints of this nature come from staff 'on the ground' and therefore people in a position to know the day-to-day management practices of homes. The Committee believes that the Agency should continue to review the nature and extent of these practices including carefully targeted spot checks.

Improved consumer focus

3.45 Evidence indicated the need for the Agency to involve residents and their families to a greater extent than currently occurs in the accreditation process and also in promoting informed consumer choice.

3.46 Prior to an accreditation visit, providers must inform residents and relatives when the visit will occur, and that residents and relatives will have an opportunity to speak with assessors in confidence. The Agency stated that assessors are required to meet with a minimum of 10 percent of residents or their representatives as part of the accreditation process. When assessors speak to residents they are required to do so in a way that does not identify residents and does not cause residents to be identified, although the Agency conceded that 'that does not mean that an approved provider of care might not be aware that certain residents had spoken to assessors'.³² The Agency asks providers to ensure that there is a private room or space available to interview residents who wish to speak to assessors. Residents are often interviewed in the privacy of their own rooms.³³

30 *Submission 105, Supplementary Information, 27.5.05 (ACSAA).*

31 *Submission 105, Supplementary Information, 27.5.05, (ACSAA). See also Committee Hansard 19.8.04, p.95 (ACSAA).*

32 *Committee Hansard 19.8.04, p.96 (ACSAA).*

33 *Submission 105, Supplementary Information, 27.5.05 (ACSAA).*

3.47 Advocacy Tasmania stated that:

Residents are often not aware of their rights to contribute to the process of accreditation or understand the level of care required to be provided by the facilities to meet each standard.³⁴

3.48 The advocacy group noted that residents are often not aware that meeting many of the 44 outcomes requires a facility to demonstrate a process of consultation with residents and family members.³⁵

3.49 The Aged Care Lobby Group argued that the proportion of residents and their families required to be interviewed by assessors should be increased.³⁶ Advocacy Tasmania also argued that the Agency should conduct a mid-cycle survey of all residents to assist in monitoring standards of care between accreditation rounds.³⁷ COTA National Seniors considered that:

Residents and their families must understand the accreditation process and be directly involved in the process not just as complainants or informants but assessing the quality of care particularly in relation to Standard 3: Resident Lifestyle.³⁸

3.50 COTA suggested that even the term 'accreditation' is a difficult concept for consumers to understand:

...it is a real challenge to get the information out to the consumer. It does get out in some way, but, from the feedback we get from people who are going through the process of looking for a place in an aged care facility, just the word 'accreditation' is wrong. How does the normal consumer know what the terms 'certification' and 'accreditation' mean? As a consumer organisation...we provide information, but still people are at a loss when it comes to knowing about accreditation.³⁹

3.51 Submissions argued that the Agency needs to improve its information strategies to residents and families from culturally and linguistically diverse (CALD) backgrounds. The NSW Aged Care Alliance noted that accreditation reports do not provide adequate information either about care strategies or outcomes for consumers

34 *Submission 158*, p.1 (Advocacy Tasmania). See also *Submission 198*, p.2 (Aged Care Lobby Group).

35 *Submission 158*, p.2 (Advocacy Tasmania).

36 *Committee Hansard 22.2.05*, p.28 (Aged Care Lobby Group).

37 *Submission 158*, p.3 (Advocacy Tasmania).

38 *Submission 174*, p.9 (COTA National Seniors).

39 *Committee Hansard 27.4.05*, p.31 (COTA National Seniors).

from CALD backgrounds.⁴⁰ Submissions also noted that the Agency's use of interpreting services during accreditation visits is limited.⁴¹

3.52 The Hogan Review suggested that the Agency needs to significantly improve its focus on supporting informed consumer choice and consumer input to monitoring standards by improving direct communication with consumers, including those with special needs. The review argued that the Agency's website should be improved to make it more 'user friendly' for older people and their families. The review also suggested that the Agency explore, with consumers and the industry, a star rating system to assist consumers to more readily compare services and to provide incentives for providers to become more competitive in providing quality services.⁴² The HSU strongly supported the introduction of a star rating system to improve informed consumer choice.⁴³

3.53 The Department advised that improvements to the Agency's website are being developed and that a prototype version has been developed. The Commonwealth has provided \$2.1 million for the development of this website and the establishment of a rating system for aged care facilities. A working group is currently undertaking further development work on this prototype. The improved website is expected to be operational in early 2006. The website aims to provide older Australians, their families and carers, with a user friendly and comprehensive online guide to aged care services and choices. The site will include features that will enable consumers to search for standard information about all aged care homes in Australia, such as location, business address, contact details, type of care provided, number of residents and current accreditation status.

3.54 Initial work has been completed on the star rating system and this is being developed in conjunction with the new website to enable consumers to search for relevant information on aged care facilities. DoHA stated that decisions have yet to be made on the form that a star rating system could take but work being undertaken on the development of the website is providing useful information about what consumers are seeking to assist them in making informed choices about meeting their, or their families', aged care needs. Research to date indicates that consumers require a system that will allow them to find and match aged care homes against their own personal criteria. Relevant factors include issues such as location of homes within a reasonable distance to family/friends; whether there are vacancies; costs involved; services offered and individualised activities provided; staff skills at homes; information on the 'environment' of the home such as type of room, shared or private bathrooms, security,

40 *Submission* 203, p.6 (NSW Aged Care Alliance).

41 *Submissions* 82, p.2 (ECCV); 178, pp.12-14 (ECC of NSW).

42 Hogan Review, pp.244-45.

43 *Submission* 122, p.22 (HSU).

access to gardens etc; safety and privacy policies and practices; languages spoken; and information related to complaints and complaints feedback.⁴⁴

Recommendation 10

3.55 That the Agency further develop and improve information provided to residents and their families about the accreditation process, including those from CALD backgrounds and Indigenous people, and more actively involve residents and their families in the accreditation process.

Recommendation 11

3.56 That the Agency develop a rating system that allows residents and their families to make informed comparisons between different aged care facilities. The Committee notes that work is being done on a web-based prototype; however it considers that the rating system should not be limited to a 'star rating' but should include easily understood descriptions of a range of attributes, such as type and range of services provided; physical features of homes; staffing arrangements; costs of care; and current accreditation status.

JAS-ANZ and the accreditation process

3.57 Many aged care providers and peak bodies representing the industry argued that accreditation services would be better provided by enabling providers to select from a range of agencies as is common in other industries, rather than through a government monopoly of these services in the form of the Aged Care Standards and Accreditation Agency, as is currently the case.

3.58 Groups such as ANHECA and ACSA argued that it would be more appropriate to bring residential care accreditation services within the Joint Accreditation Service-Australia and New Zealand (JAS-ANZ) framework.⁴⁵ JAS-ANZ would be responsible for accrediting a number of quality improvement organisations to undertake accreditation in the residential care sector. An open contestable quality improvement environment would also provide a further benefit to the residential care sector. Many providers of residential care are also providers of other services to older people, including community aged care packages, Home and Community Care programs, retirement villages and other community based and residential programs for the elderly and others. Under current arrangements they are required to participate in multiple accreditation systems to cover the whole scope of their activities. This problem would be addressed if a market in the provision of

44 DoHA, personal communication, 6.6.05; Supplementary Information, 20.6.05 (DoHA).

45 JAS-ANZ was established by formal agreement between the Governments of Australia and New Zealand. Its main activity is the assessment and accreditation of certification bodies.

accreditation services were allowed to be developed to respond to the industry's wider accreditation needs.⁴⁶

3.59 Other providers, including CHA, did not favour this approach. CHA argued that providers would be dealing with another party in the accreditation/compliance processes with possibly greater intrusion and disruption to staff time. In addition, there could be an increase in costs when two agencies have responsibility for two separate accrediting/compliance monitoring tasks.⁴⁷ CHA added that:

Allowing a number of accredited certifying organisations to compete to provide accreditation of an approved service and have responsibility to the Government for compliance would result in even less consistency of assessments and decisions. CHA considers that neither consumers nor the community would accept this approach.⁴⁸

3.60 The Committee does not support the suggestion proposed by several providers of allowing a range of agencies to provide accreditation services. It believes that such an approach has the potential to lead to greater inconsistency in assessment outcomes by involving a greater number of organisations in providing accreditation services. The Committee also considers that it may encourage providers to 'shop around' for a 'soft' auditor and is not convinced that the JAS-ANZ arrangements would militate against this potential outcome.

Improved compliance monitoring

3.61 The need for the Agency to improve compliance monitoring of aged care facilities between accreditation periods was raised in evidence. As noted above, aged care facilities are subject to a regular series of support contacts to monitor their ongoing compliance with the Accreditation Standards.

Support visits

3.62 Some providers criticised the way in which support visits are conducted by the Agency arguing that they are intimidating experiences and did not provide the 'support' expected – in fact some argued that the term 'support visit' was a misnomer. CHA noted that many of its members' experience of support visits 'had not been positive' reporting that 'there was a general view that support visits have not provided any 'support' and in fact hindered processes'.⁴⁹ ACS SA & NT commented that some members feel intimidated by support visits 'believing that if they do not comply, or object to the timing of the visit there will be retribution against them by the Agency'.⁵⁰

46 *Submissions* 74, pp.8-10 (ANHECA); 173, pp.3-4 (ACSA). See also *Submissions* 150, pp.10-12 (VAHEC); 170, pp.11-12 (ACS of NSW & ACT).

47 *Submission* 166, p.7 (CHA).

48 *Submission* 166, p.7 (CHA).

49 *Submission* 166, p.8 (CHA).

50 *Submission* 125, p.7 (ACS SA & NT).

The organisation noted, however, that members report more positive experiences of more recent support visits.⁵¹

3.63 The Agency's post-support visit questionnaires, however, indicate a high level of support with the role of the Agency during these visits – with a 2004 questionnaire indicating that 96 per cent of homes reported that it was 'a satisfying and useful experience' overall.⁵²

3.64 The Committee notes that some concerns have been expressed by providers in regard to the efficacy of support visits. The Committee believes that the Agency should ensure that these visits, while monitoring compliance, also assist in providing positive feedback to homes.

Spot checks

3.65 As referred to previously, the Agency is required to visit each home at least once a year and maintain an average visiting schedule of 1.25 visits per home per annum. These visits may either be site support contacts or review audits – and they may be conducted as spot checks. Additional visits are arranged where the Agency assesses that there is a need for more visits such as a reason for concern or serious risk has been identified.⁵³

3.66 Approximately 15 per cent (553) of all Agency visits in 2003-04 were conducted as spot checks. Of the 'repeat' spot checks in 2003-04, thirty-eight homes had 2 spot checks; eight had 3 spot checks; four had 4 spot checks; and six had 5 or more spot checks.

3.67 Spot checks may be targeted or random. Targeted spot checks are conducted where the Agency has reasonable grounds to believe there may be non-compliance, whereas random spot checks are conducted where there is no indication of risk or non-compliance. The Agency does not keep separate statistics on random and targeted spot checks. On average approximately 10 per cent of homes per annum will have an unannounced spot check.⁵⁴ Table 3.1 provides the number of spot checks undertaken by the Agency since 1999-2000.

51 *Committee Hansard* 22.2.05 p.3 (ACS SA & NT).

52 *Submission* 105, Attachment B (ACSAA).

53 *Submission* 105, Supplementary Information, 27.5.05 (ACSAA).

54 *Submission* 105, Supplementary Information, 27.5.05 (ACSAA); Annual Report, p.22.

Table 3.1: Number of spot checks undertaken by the Accreditation Agency

Year	Number of spot checks
1999 – 2000	107
2000 – 2001	360
2001 – 2002	449
2002 – 2003	242
2003 – 2004	553

Source: Aged Care Standards and Accreditation Agency, *Annual Reports*, (various years).

3.68 A number of groups argued that the Agency should undertake more spot checks. The HSU argued that:

...members consistently argue that spot checks or checks without notice would be more effective than the current scheduled visits. Members tell us that often management select the staff who are to speak with the accreditors when they come. Members advise that additional staff are rostered on and that much effort in the weeks leading up to accreditation goes on making sure that paperwork and documentation are up to date.⁵⁵

3.69 Aged care provider peak bodies acknowledged the value of spot checks in ensuring compliance with the Standards, with Aged Care Qld proposing a more comprehensive system of spot checks instead of organised visits.

We have talked to the accreditation agency and we have talked to many of our people, and we think that perhaps this whole system needs to be looked at. Perhaps we need to do away with having organised visits and instead have spot checks. The accreditation agency would drop in at any particular time and take the home as it is, not superprepared for the event.⁵⁶

3.70 Aged and Community Services Australia (ACSA), while noting that spot checks are a valuable form of accountability, argued that the Agency needs to improve the way in which it conducts its spot checks:

We certainly have talked to them [the Agency] about developing more refined approaches to spot checking, to targeting, to being clear about which visits are about providing support and training and which are in response to urgent issues that really cannot wait...Follow-up visits are a feature of all forms of accreditation. Certainly our advocacy of a more

55 *Committee Hansard* 19.8.04, p.65 (HSU). See also *Submission* 122, p.22; *Committee Hansard* 26.4.05, p.46 (HSU).

56 *Committee Hansard* 18.3.05, p.14 (Aged Care Qld).

universal system of applying accreditation would not be at the expense of follow-up visits of all sorts of classes.⁵⁷

3.71 Aged Care Qld argued that a system of spot checks could potentially ameliorate the heavy demands of paperwork imposed on homes under the current accreditation system.⁵⁸ Evidence also indicated that more spot checks would identify possible problems in homes, such as poor medication management, much earlier than occurs at present.⁵⁹

Conclusion

3.72 The Committee believes that spot checks play an important role in ensuring compliance with the Accreditation Standards. It is vital that residents and their families, and the public generally, are confident that the standards of care assessed when homes are accredited are maintained at all times until the next accreditation round.

3.73 The Committee believes that the current system of spot checks is inadequate and needs to be considerably strengthened to ensure that all homes receive at least one spot check for each year that they are accredited. The Committee considers the fact that only one in 10 homes on average receive a spot check per year is grossly inadequate.

Recommendation 12

3.74 That the Agency ensure that all facilities be subject to a minimum of one annual random or targeted spot check and at least one site visit with notification over its accredited period.

Improving quality of care

3.75 The need to improve specific aspects of care in aged care facilities was highlighted during the inquiry.

3.76 As noted earlier, a core Agency function is the accreditation of aged care facilities against the Accreditation Standards. The Quality of Care Principles state that:

The Accreditation Standards are intended to provide a structured approach to the management of quality and represent clear statements of performance. They do not provide an instrument or recipe for satisfying expectations but, rather, opportunities to pursue quality in ways that best suits the characteristics of each individual residential care facility and the

57 *Committee Hansard* 26.4.05, p.7 (ACSA).

58 *Committee Hansard* 18.3.05, pp.17-18 (Aged Care Qld).

59 *Committee Hansard* 22.2.05, p.32 (Aged Care Lobby Group).

needs of residents. It is not expected that all residential care facilities should respond to a standard in the same way.⁶⁰

3.77 It was claimed in evidence that the Standards are too imprecise and far too generalised to effectively measure care outcomes. The HSU stated that the Accreditation Standards 'need to be rewritten so that they are measurable and enforceable'.⁶¹ The Aged Care Lobby Group also noted that while the Accreditation Standards assess standards of care to some extent – 'it needs some refinement. It is too subjective. It relies on what is written by the provider and statements by relatives and residents.'⁶²

3.78 A study by Professor Gray also noted that:

To the extent that the Agency does not assess actual care delivered, but infers it from the information provided by residents, staff, families and relevant documentation, its capacity to provide objective information around care outcomes is limited.⁶³

Issues related to the quality of care in a range of specific areas are discussed below.

Staffing levels and skills mix

3.79 Submissions pointed to inadequate staffing levels and poor skills mix in aged care facilities as compromising the quality of care available to residents. The Accreditation Standards do not prescribe minimum staffing levels in aged care facilities. The Accreditation Standards only require that there be 'appropriately skilled and qualified staff sufficient to ensure that services are delivered in accordance with these standards' (Standard 1.6) and that residents receive 'appropriate clinical care' (Standard 2.4) and that residents' 'specialised nursing care needs are identified and met by appropriately qualified nursing staff' (Standard 2.5).

3.80 The ANF noted that staffing levels and the skills mix of staff impact directly on the workloads of nurses and ultimately on the quality of health outcomes for residents. The ANF expressed concern that there are increasingly fewer registered nurses (RNs) and enrolled nurses (ENs) in aged care facilities and some high care residents in low care facilities have very limited or no access to a health care professionals such as RNs. The ANF also expressed concern at the practice of replacing RNs and ENs with unlicensed carers in order to provide a 'cheaper' alternative workforce where the work requires the skills and knowledge of either a RN or an EN.⁶⁴

60 Quality of Care Principles, section 18.9.

61 *Submission 122*, p.22 (HSU).

62 *Committee Hansard 22.2.05*, p.29 (Aged Care Lobby Group).

63 Gray L, *Two Year Review of Aged Care Reforms*, DoHA, 2001, p.91.

64 *Submission 201*, pp.16-18 (ANF). See also *Submission 122*, p.18 (HSU).

3.81 Submissions by unions with members working in the aged care sector pointed to evidence from their members and union surveys that show that nurses and other health care workers do not believe that they are able to spend enough time with residents to deliver the care that residents require; aged care workers regularly work unpaid overtime to complete tasks; and the excessive paperwork required places increasing demands on staff and draws them away from their primary caring role.⁶⁵ A recent survey of over 6000 care staff by the National Institute of Labour Studies confirmed these observations. The study found that:

- only 13 percent of nurses and 18 per cent of staff overall believed that they had enough time to properly care for residents;
- forty per cent of nurses and 25 per cent of allied health workers spend less than one third of their time providing direct care;
- almost half of all personal carers spend less than two-thirds of their time on direct care; and
- the major complaints of staff were that they did not have enough time to spend with residents and the facility where they worked did not employ sufficient staff.⁶⁶

3.82 The HSU argued that international research establishes a clear link between staffing levels and quality of care.⁶⁷ A major report to the US Congress on the appropriateness of establishing minimum staffing ratios in nursing homes in the United States concluded that strong evidence supports the relationship between increases in nurse staffing ratios and avoidance of critical quality of care problems. However, above identified nurse staffing thresholds increased staffing did not result in improved quality. Depending on the nursing home population, these thresholds range between 2.4-2.8, 1.15-1.30, and 0.55-0.75 hours/resident day for nurse aides, licensed staff (RNs and LPNs combined) and RNs, respectively. Although no significant quality improvements were observed for staffing levels above these thresholds, quality was improved with incremental increases in staffing up to and including these thresholds.⁶⁸

3.83 Some submissions, however, did not support the introduction of minimum staffing levels arguing that appropriate care depends on a range of variables that change frequently. The Nurses Board of WA stated that:

65 *Submissions* 122, pp.2-10 (HSU); 179, pp.6-7 (NSW Nurses' Association); 59, pp.7-11 (HSU - NSW Branch).

66 Richardson S & Martin B, *The Care of Older Australians*, National Institute of Labour Studies, 2004, pp.32-34.

67 *Submission* 122, p.3 (HSU). See also *Submission* 66, p.2 (ANF- Vic Branch).

68 US Department of Health & Human Services, *Report to Congress: Appropriateness of Minimum Nurse Staffing Ratios in Nursing Homes*, December 2001, pp.1.19-1.20. LPNs refer to Licensed Practical Nurses.

The Board gets many requests by employers to come down and make a statement about minimum numbers. However, the Board is very much of the view that it is the appropriate skill mix in the context of where the care is being delivered that determines what you require at any given time. That is not helpful to employers and it is not helpful to the staff on the floor. But the context in which aged care is delivered is varied and it depends on a whole range of variables.⁶⁹

3.84 Many submissions argued that a benchmark of care linked to minimum staffing levels should be established. The ANF argued that a benchmark of care which links resident outcomes, staffing levels and skills mix to funding should be developed for inclusion in regulatory instruments. The ANF further argued that guidelines should be developed providing for minimum staffing levels and skills mix in aged care settings and that there be a clear requirement for 24 hour RN cover for all high care residents in aged care facilities.⁷⁰

3.85 The National Aged Care Alliance also called for the establishment of benchmarks for staffing levels and skills mix, which meet duty of care requirements; achieve optimal health and quality of life outcomes for residents; and provide flexibility at the local level to be able to respond in a timely manner to changes in the care needs or the way in which care is delivered.⁷¹

3.86 The Liquor Hospitality and Miscellaneous Union (LHMU) also argued for a national benchmark of care. This would encompass all aspects of care, including establishing minimum staffing levels and skills mix in delivering care. The benchmark of care, which would be fully costed, could be used as the tool to determine the funding that the government provided for care.⁷²

3.87 The HSU also argued for the introduction of minimum staffing levels that should only be introduced after a process of industry consultation that involved providers, staff and residents – 'they would not be a one size fits all but a regulated minimum number determined by resident needs and acuity' involving a mix of nurses and personal care assistants in caring for residents.⁷³ The HSU added that:

Those minimum staffing levels need to be flexible so that they can be adjusted for the particular care plans and circumstances of each facility. But underlying that there has to be a stage when government says: 'One person looking after 73 residents at night when 43 of them are high care is not something that as taxpayers we are going to fund'.⁷⁴

69 *Committee Hansard* 23.2.05, p.18 (Nurses Board of WA).

70 *Submission* 201, p.2 (ANF).

71 National Aged Care Alliance, Additional Information, 20.4.05.

72 *Submission* 124, p.18 (LHMU).

73 *Submission* 122, p.14 (HSU)

74 *Committee Hansard* 26.4.05, p.49 (HSU).

3.88 The HSU argued that the regulatory requirements for staffing, stripped away by the current government, need to be re-introduced and significantly extended – 'minimum staffing levels covering all care and ancillary staff are the only way to provide a basic guarantee of care and safety for residents and their families'.⁷⁵

3.89 CHA also proposed a quality of care compact based on an agreed level of care which commits government, providers and staff to achieve specific care results for the frail and sick. A key component would be the establishment of an aged care benefit schedule to modernise government care subsidies and to deliver appropriate support to the frail elderly. CHA stated that:

...a compact would include a commitment to introducing a benchmark of care which is fully funded by government and provides clearly defined levels of service. It is linked to the benchmark. There needs to be a commitment of funding to ensure appropriate staffing levels are in place for facilities, depending on their size, and the resident profile. The benchmark of care needs to take into account all aspects of a person's needs: physical, emotional, social and spiritual.⁷⁶

3.90 CHA further explained how the benchmark of care would operate.

Under the benchmark of care approach, what we would be saying is that there are certain dependency levels and clinical groupings of care need for residents. When you have a group of residents that are in a similar care cohort or casemix, then you really need a mix of staff to meet that care need for that particular casemix of residents.⁷⁷

Conclusion

3.91 Evidence to the inquiry indicated that quality of care for residents in aged care facilities could be improved by the introduction of greater regulation in relation to staffing levels and skills mix in aged care facilities. Many submissions argued for the introduction of a benchmark of care or a quality of care compact that links resident outcomes, staffing levels and skills mix.

3.92 Evidence indicates that the introduction of such a system would ensure that realistic staffing levels are in place in aged care facilities. The Committee believes, however, that such a system would need to be sufficiently flexible to take into account the changing needs of residents.

Recommendation 13

3.93 That the Agency, in consultation with the aged care sector and consumers, develop a benchmark of care which ensures that the level and skills mix of staffing at each residential aged care facility is sufficient to deliver the

75 *Submission 122*, p.14 (HSU).

76 *Committee Hansard 11.2.05*, pp.4-5 (CHA).

77 *Committee Hansard 11.2.05*, pp.11-12 (CHA).

care required considering the needs of the residents. The benchmark of care that is developed needs to be flexible so as to accommodate the changing needs of residents.

Access to medical and allied health workers

3.94 Submissions referred to the difficulty in attracting doctors and other health professionals to attend to the medical needs of residents in aged care facilities. The Australian Society for Geriatric Medicine (ASGM) noted 'older people in residential care facilities are significantly disadvantaged and have poor access to both basic medical care and specialist medical care'.⁷⁸ The Australian Medical Association (AMA) noted that only 16 per cent of GPs are visiting nursing homes on more than 50 occasions a year – that is once a week.⁷⁹

3.95 The AMA noted that disincentives for health professionals in providing care in nursing homes included lack of remuneration, a deficient rebate structure for doctors, the absence of appropriate MBS items for geriatricians, the large amount of paperwork required by aged care facilities and the absence in many facilities of consultation rooms with adequate treatment facilities and computer facilities to facilitate access to patient records.⁸⁰ Witnesses commented that the Aged Care GP Panels Initiative announced in November 2003, which aims to improve access to primary medical care for residents of aged care homes, has only been successful in some areas in attracting GPs to aged care facilities either because of the shortage of GPs in general and a reluctance by some GPs to provide services in nursing homes.⁸¹

3.96 The ASGM noted that few geriatricians or other specialists are prepared to work in aged care facilities and pointed to the fact that a GP assessment in a facility is now remunerated at a higher level than a complex, comprehensive specialist geriatric assessment. In addition, there are few geriatricians who consider residential care their area of particular interest in geriatric practice. The ASGM noted that 'the best models of care focus on a multidisciplinary approach to care, with allied health, nursing and medical practitioners working together. That does not happen in this country in residential care'.⁸²

3.97 Residents in aged care facilities are required to have access to a range of specialist care including speech therapy, podiatry, occupational care and physiotherapy. The Accreditation Standards state that residents be referred 'to appropriate health specialists in accordance with the resident's needs and preferences'

78 *Committee Hansard* 19.8.04, p.35 (ASGM).

79 *Committee Hansard* 11.2.05, pp.21,28 (AMA).

80 *Committee Hansard* 11.2.05, pp.21-21 (AMA); *Submission* 129, p.5 (AMA).

81 *Committee Hansard* 11.2.05, pp.13-14 (UnitingCare Australia); 22.2.05, pp.54-55 (Regional Medication Advisory Committee).

82 *Committee Hansard* 19.8.04, p.35 (ASGM).

(Standard 2.6), although evidence indicated that there are huge variations in the quality and provision of these services. The Australian Physiotherapy Association (APA) expressed concerns that the Agency places insufficient emphasis on ensuring the presence of preventive programs and that therapy is properly provided in facilities. The APA noted that some aged care facilities that advertise a comprehensive physiotherapy service do not employ sufficient physiotherapists to provide this service.⁸³ The Australian Psychological Society called for the increased use of psychologists in aged care facilities especially in the areas of mood and anxiety problems and physical disorders. The Society argued that psychologists have little current role in aged care despite the effectiveness of psychological interventions in these situations.⁸⁴

3.98 The provision of adequate dental care was also cited as a problem in aged care facilities. The Accreditation Standards require that residents' 'oral and dental health is maintained' (Standard 2.15). The Aged Care Lobby Group noted that 'oral care is often lacking and as a follow-on...there are dental problems' for residents in homes.⁸⁵ The CPSA also noted that studies have reported poor dental care in nursing homes and commented that this situation was 'not exactly a glowing testimony to the way accreditation is carried out'.⁸⁶

Medication management

3.99 A number of issues in relation to medication management were raised in evidence including significant problems regarding medication use in aged care facilities. These include selection of management options, prescribing decisions, administration and use of pharmaceuticals and the lack of ongoing review and follow-up of residents.⁸⁷ The Accreditation Standards provide that residents' medication 'is managed safely and correctly' (Standard 2.7). The Australian Pharmaceutical Advisory Council's *Guidelines for Medication Management in Residential Aged Care Facilities* (2002) provide guidelines about improving the quality use of medicines in aged care facilities. It was suggested that, while the facilities pick up on those guidelines as part of the accreditation process, 'there are very major gaps...between what is recommended in guidelines and what actually happens in practice'.⁸⁸

3.100 There was evidence to suggest that medication is used in some aged care facilities to deal with a range of behavioural and other problems that could best be

83 *Submission 72*, pp.3-4 (APA).

84 *Submission 207*, pp.1-3 (Australian Psychological Society).

85 *Committee Hansard 22.2.05*, p.32 (Aged Care Lobby Group). See also 19.8.04, p.41 (ASGM).

86 *Submission 79*, p.6 (CPSA).

87 *Submission 120*, Supplementary Information, 22.2.05 (Adelaide NE Division of General Practice).

88 *Committee Hansard 22.2.05*, p.52 (Adelaide NE Division of General Practice Regional MAC).

dealt with by other approaches. The Australian Society for Geriatric Medicine noted that:

The problem of polypharmacy and drug use is a very serious and significant one in residential care facilities, and in part it comes from the ignorance and skill mix of those who provide care. The answer to behavioural problems in patients with dementia, for example, is not to give them antipsychotic medications but to put in place appropriate behavioural and environmental strategies.⁸⁹

3.101 One submission also pointed to studies that show CALD residents with dementia in generic aged care facilities are often over medicated with sedatives, although this is a less serious problem for CALD residents in ethno-specific facilities.⁹⁰

3.102 The ASGM suggested that medication use in aged care facilities could be improved if a multidisciplinary approach was adopted involving doctors, nursing staff, geriatricians, with pharmacy input 'in order to help work out what is the best evidence in terms of treatment approaches...we have really fallen short of having a proper multidisciplinary approach to medication management'.⁹¹

3.103 The issue of the relative effectiveness of different medication systems was raised in evidence, especially possible means of streamlining the process. The Centre for Research into Aged Care Services conducted a study into a comparison of two types of medication administration systems, particularly in terms of the time and resources involved in the two systems. One was the traditional dosette box and the other was the computerised sachet. The study found that with the computerised delivery system 'there were fewer errors, there was more confidence with the people dispensing the medications and they were able to move away from the big trolley and all that stuff that takes up time'.⁹²

Nutrition

3.104 Advocacy groups and others commented on the poor standard of food in some aged care facilities, although these groups could not provide substantive evidence of the extent of the problem throughout the industry.⁹³ The Dietitians Association of Australia stated that the Agency in recent years has given increasing attention to

89 *Committee Hansard* 19.4.04, p.41 (ASGM).

90 *Submission* 224, p.6 (Fronditha Care); *Committee Hansard* 27.4.05, p.44 (Fronditha Care).

91 *Committee Hansard* 19.8.04, p.41 (ASGM).

92 *Committee Hansard* 23.3.05, pp.10-11 (Centre for Research into Aged Care Services).

93 *Committee Hansard* 28.4.05, pp.2-15 (Advocacy Tasmania); 22.2.05, pp.28-32 (Aged Care Lobby Group).

nutrition standards in aged care facilities and more dieticians are now employed directly by facilities than in the past.⁹⁴

3.105 Complaints to the inquiry included poor quality of the food, lack of variety, and lack of fresh food in some facilities. Poor nutrition can lead to a range of health problems. The Accreditation Standards merely require that residents receive 'adequate nourishment and hydration' (Standard 2.10).

3.106 The importance of good quality food for residents was emphasised by the Aged Care Lobby Group:

Most people never see fresh fruit in a nursing home unless it is brought by relatives. For elderly people, and for us all, food is a celebration and we hang our day on what we are going to have...That is one of the real pleasures that most aged care facilities do not provide.⁹⁵

3.107 Groups argued that that Standards in relation to food and nutritional care need to be further defined or enhanced.⁹⁶ The Aged Care Lobby Group suggested that a committee should be established to assess the nutritional needs and types of food that should be available in homes.⁹⁷ The Dieticians Association also argued that the Agency should consult with the profession on continuous improvement in assessment and review processes of the Standards.⁹⁸

Transport needs

3.108 Submissions noted the lack of accessible and affordable transport options available to people in residential aged care.

3.109 NCOSS, in a report on the transport needs of people in aged care facilities in NSW, found that:

- most residents relied on family and friends as their primary source of transport support;
- a third of residents reported having no significant access to family and friends and thus great difficulty in accessing transport support;
- many residents would prefer to use transport services more often to travel to appointments and outings;

94 *Submission* 184, p.3 (Dietitians Association).

95 *Committee Hansard* 22.2.05, pp.29-30 (Aged Care Lobby Group).

96 *Committee Hansard* 22.2.05, p.32 (Aged Care Lobby Group); *Submission* 184, p.4 (Dietitians Association).

97 *Committee Hansard* 22.2.05, p.29 (Aged Care Lobby Group).

98 *Submission* 184, p.4 (Dietitians Association). See also *Committee Hansard* 22.2.05, p.42 (Healthy Ageing Project).

- a major barrier to travel for many older residents was the lack of an accompanying escort;
- people from CALD backgrounds were unlikely to use transport services other than family;
- there were significant inequities in access and eligibility to subsidised taxi transport; and
- many facilities had great difficulty in providing available, affordable and accompanied transport services for residents.

3.110 The NCOSS study recommended that more information needs to be provided to residents on their rights in relation to transport and the options available upon entry to nursing homes and that this information be provided on a regular ongoing basis; that additional funding be available for the taxi subsidy scheme and that the eligibility criteria for the scheme be expanded; and that a more coordinated approach be adopted for the effective use of existing transport resources.⁹⁹

3.111 The NSW Aged Care Alliance noted that, while aged care providers carry some responsibility for providing transport services to residents, current funding levels do not adequately cover the costs of providing residents with appropriate transport options.¹⁰⁰ NCOSS proposed the introduction of a residential aged care transport supplement. This supplement to be funded by the Commonwealth – and be similar to other supplements under the Aged Care Act – would provide a dedicated funding allocation towards transport support for people living in aged care facilities.¹⁰¹

Needs of people from culturally and linguistically diverse backgrounds

3.112 Submissions and other evidence from groups representing people from culturally and linguistically diverse (CALD) backgrounds argued that the Accreditation Standards do not adequately address the needs of residents from these backgrounds. Fronditha Care noted that:

The current regulatory framework...is deafening in its silence on the importance of language and cultural identity, to service delivery and the experience of CALD elders.¹⁰²

3.113 The projected demographic profile of Australia's CALD population indicate significant increases in demand for aged and community services over the next 20 years. Currently the number of elderly from CALD backgrounds is 20 per cent of

99 *Submission* 204, Appendix 1 (NCOSS).

100 *Submission* 203, pp.17-18 (NSW Aged Care Alliance).

101 *Submission* 204, Appendix 1 (NCOSS).

102 *Submission* 224, p.4 (Fronditha Care & DutchCare). See also *Committee Hansard* 27.4.05, pp.38-42 (ECC of Victoria/Fronditha Care).

the population aged 65 years and over. This is projected to increase to 23 percent, or almost a quarter of the aged population 65 years and over, by 2016.¹⁰³

3.114 Submissions noted that only one of the 44 expected outcomes makes reference to cultural identity (Resident Lifestyle Standard 3.8) and there is no mention at all in relation to language and the importance of communication in the residents' own language. One witness cited the example of elderly Greek-speaking women in their mid-80s who speak very little English:

They are in a mainstream nursing home for 24 hours a day, 365 days of the year...how does this elderly person connect with their carers and with the social system that forms that nursing home or hostel? If you do not have the language and if you do not share a common sense of history, values, music or food...then it is an extraordinarily isolating experience.¹⁰⁴

3.115 Submissions also noted that often the Agency assessors do not utilise interpreting services during their assessment visits to facilitate effective communication with residents who do not speak English and therefore argued that they would be unable to obtain adequate feedback from residents as to whether their needs are being met.¹⁰⁵

3.116 The Agency stated that when visiting services that cater for specific, or large numbers of CALD residents, 'it may be appropriate' to engage the services of a translator to assist assessors to communicate effectively with residents. The decision to engage a translator rests with the local State manager and will be based on information collected regarding the dominant cultures and languages used in the service. It may also be appropriate to discuss the need for a translator with the provider at the service. The Agency noted that 'it is not practical' for it to provide a translator for every cultural group or language group in a particular service.¹⁰⁶

3.117 Submissions and other evidence argued that the Accreditation Standards need to address the needs of CALD residents in the following areas:

- Cultural diversity needs to be effectively addressed across all the Standards, as all are relevant in meeting the full range of individual care and health needs of CALD residents.
- Specific expected outcomes need to be introduced relating to the language and communication needs of CALD residents.
- Agency auditors should be trained in cultural competency in aged care service provision. 'Cultural competence' refers to the ability of an individual to function effectively in cross-cultural situations taking into account the culture,

103 *Submission* 178, p.4 (ECC of NSW).

104 *Committee Hansard* 27.4.05, p.38 (Froniditha Care).

105 *Submissions* 82, p.2 (ECCV); 224, p.4 (Froniditha Care).

106 *Submission* 105, Supplementary Information, 27.5.05 (ACSAA).

lifestyles and experiences of the particular individuals with whom they are interacting.

- The Agency should develop and utilise standard cultural competence assessment tools.
- A designated position to represent CALD residents should be created on the Board of the Agency.¹⁰⁷

3.118 Regarding the qualifications of assessors, the Agency stated that some registered assessors do have specific knowledge or language skills for certain CALD groups – 'whenever possible these assessors should be used as part of a team'. Cultural factors, language and ethnicity is included in the attributes identified for quality assessor registers. The Agency also maintains its own list of staff who speak a language other than English.¹⁰⁸

Needs of Indigenous aged people

3.119 Evidence indicates that the needs of aged Indigenous Australians are currently not being met in many aged care facilities. Some witnesses called for the construction of more Indigenous-specific aged care facilities in areas of large Aboriginal populations or the construction of specific wings in local nursing homes in other areas. There are only two Indigenous-specific residential care facilities in NSW.

3.120 Evidence pointed to the need for culturally appropriate residential aged care that is conveniently located. One witness noted that:

We have a lot of people out west [of NSW] who want – who need – to go into residential care and just cannot access to it, because it means leaving their homes, their regions and their families. Aboriginal communities and Aboriginal people do not particularly want residential care anyway, but when we get to the point where we need it, we would like to be able to have something that is culturally appropriate, that is close by and that has Aboriginal workers providing that care.¹⁰⁹

3.121 Evidence also emphasised the importance of Indigenous staffing of aged care facilities:

Aboriginal staff actually address a lot more issues than just carrying out their required duties – it entails the emotional care of our elders, which no non-Aboriginal person with any amount of cultural awareness can address. There are also our historical conversations, if you like – some of our elders

107 *Submissions* 178, pp.12-14 (ECC of NSW); 82 p.2 (ECCV); 224, p.4 (Fronditha Care); 203, p.6 (NSW Aged Care Alliance); *Committee Hansard* 11.3.05, pp.1, 4-5 (ECC of NSW).

108 *Submission* 105, Supplementary Information, 27.5.05 (ACSAA).

109 *Committee Hansard* 11.3.05, p.49 (NSW Aboriginal Community Care Gathering).

with dementia go back to things that happened in the past. Aboriginal people are much more empathetic...and we deal with it much better.¹¹⁰

3.122 Witnesses also commented that where non-Aboriginal staff are employed they should be trained in cultural competency and be aware of cultural issues relevant to Indigenous aged people.

Conclusion – how effective are the Accreditation Standards?

3.123 Evidence indicates that in a range of areas from medication management to access to medical services there are significant problems in the provision of services to residents in aged care facilities.

3.124 It was suggested in evidence that the Accreditation Standards are failing to measure areas where care is clearly deficient. The Committee believes that the Accreditation Standards are too generalised to effectively measure care outcomes. The wording of the Standards necessarily lead to varying levels of service being provided in homes because the Standards are open to widely different interpretations by proprietors and assessors. The Committee believes that the Accreditation Standards need to be defined more precisely so that standards of care in aged facilities can be delivered – and measured – in a consistent manner across all aged care facilities.

Recommendation 14

3.125 That the Commonwealth, in consultation with industry stakeholders and consumers, review the Accreditation Standards to define in more precise terms each of the Expected Outcomes and that this review:

- **address the health and personal care needs of residents, especially nutrition and oral and dental care; and**
- **include specific consideration of the cultural aspects of care provision, including the specific needs of CALD and Indigenous residents.**

Recommendation 15

3.126 That the Agency make greater use of interpreters during accreditation visits to aged care facilities, especially those facilities that cater for specific or predominant numbers of CALD or Indigenous residents; and that assessors be trained in cultural competency as part of their formal training courses.

Complaints mechanisms

3.127 A number of complaints mechanisms operate for people concerned about possible breaches of a provider's responsibilities under the Aged Care Act. All aged care services are required to establish an internal complaints system. The Aged Care Complaints Resolution Scheme (CRS) also operates to enable people to formally raise

110 *Committee Hansard* 11.3.05, pp.49-50 (NSW Aboriginal Community Care Gathering).

concerns about aged care services. DoHA also funds aged care advocacy services in each State. These services provide independent advocacy and information to residents of aged care services and family members.

Complaints Resolution Scheme

3.128 The Complaints Resolution Scheme enables people to raise concerns about aged care services funded by the Commonwealth Government, including Community Aged Care Packages (CACPs), residential care and flexible services. The Scheme is based on alternative dispute resolution principles and provides an opportunity to both parties to address a grievance in a way that enhances or rebuilds the relationship between the provider, the care recipient and their family. The Scheme, which is free, offers a means of making a complaint, independent from a residential facility. Complaints can be made verbally or in writing and can be dealt with in an open, confidential or anonymous basis. A national toll free number is available to ensure people have access to the scheme.

3.129 Resolution processes under the Scheme include preliminary assessment which is handled by complaints resolution officers prior to the acceptance or non-acceptance of a complaint; negotiation is managed by complaints resolution officers; mediation is conducted by qualified, external officers; determination of complaints is conducted by committees, which are constituted of independent members with skills in aged care and complaints resolution, where complaints cannot be resolved through negotiation or mediation; and determination review and oversight of the Scheme is conducted by the Commissioner for Complaints.

3.130 The Scheme is administered by DoHA. The Commissioner for Complaints has a statutory requirement to oversight the effectiveness of the Scheme. The Commissioner also deals with complaints about the operation of the Scheme; manages the determination process; and promotes an understanding of the Scheme.

3.131 As noted above, all aged care services are required to establish an internal complaints system and advise care recipients of any other mechanisms available to address complaints as well as providing such assistance as the care recipient requires to use those mechanisms.¹¹¹

3.132 Some evidence suggested that the internal complaints system is less than satisfactory while other evidence suggested it operates effectively. The Aged Care Lobby Group noted that 'some homes have very good internal complaints mechanisms which make it unnecessary to go to the complaints resolution unit'.¹¹² The Group

111 Commissioner for Complaints, *Annual Report 2003-04*, pp.8-13; *Submission 191*, pp.14-15 (DoHA).

112 *Committee Hansard 22.2.05*, p.33 (Aged Care Lobby Group).

noted, however, that in some instances family members have found the internal complaints system 'unsatisfactory'.¹¹³

3.133 In 2003-04, the CRS received 967 complaints. This represents a 21 per cent reduction in the number of complaints over 2002-03. The Commissioner for Complaints argued that the principal reasons for the decline were the increased use of internal complaint mechanisms and ongoing refinement in the practices adopted by the Scheme.¹¹⁴ The Committee notes, however, that statistics are not kept on the number of internal complaints.

3.134 The majority of complaints (97 per cent) related to residential aged care services and 3 per cent related to CACPs. Relatives lodged the majority of complaints (67 per cent). Nine per cent of complaints were lodged by staff, while care recipients lodged eight per cent of complaints. Some 126 complaints (13 per cent) of all complaints were not accepted by the Scheme. A complaint may be refused if it is frivolous or vexatious; the matter is subject to legal proceedings; or there is an alternative way of dealing with the subject matter of the complaint and the complainant agrees to have the matter dealt with in that way. The majority of complaints are resolved by negotiation and/or referral, 2 per cent through mediation by an independent mediator, and 3 per cent are finalised by a determination by a committee.

3.135 The nature of complaints are becoming more complex and multifaceted. Complaints have changed from concerns about single issues such as laundry, cleaning and catering to more intricate issues such as security of tenure, clinical care, medication, resident safety and communication and management. The main complaint issues raised in 2003-04 were health and personal care (300 complaints), consultation and communication (240), physical environment (180), choice and dignity (170), personnel (150) and medication management (100).¹¹⁵

Concerns with the Complaints Resolution Scheme

3.136 A number of concerns were raised in relation to the operation of the Scheme. Submissions argued that the complaints mechanisms often do not work in the interests of consumers, and the mechanisms are unclear, unnecessarily complex and in some cases complaints are actively discouraged.¹¹⁶

3.137 Evidence indicates that the CRS needs to become more accessible and responsive to consumers.

113 *Submission* 198, p.2 (Aged Care Lobby Group).

114 Commissioner for Complaints, *Annual Report*, p.23.

115 Commissioner for Complaints, *Annual Report*, pp.23-30.

116 *Submissions* 204, p.5 (NCOSS); 203, pp.6-7 (NSW Aged Care Alliance).

3.138 The Committee received an example of a concerned citizen who tried to make a complaint about an incident at a nursing home and found the whole process extremely harrowing.

...[I] wrote to the Department of Health and Ageing. I got a standard reply, saying, 'Please go to the Aged Care Complaint Resolutions Scheme'. The standard letter – everything was standard. I rang the number. It was one of those 'you want this, buzz number 1 or 2', and I thought, 'If I were an NESB person I would probably not have a clue how to do that.' I finally got onto that, and again they were saying, 'You have to get onto the mediation action.' I said: 'No, I am not a relative of the nursing home resident or anything. I am just a concerned member of the public.'¹¹⁷

3.139 NCOSS noted that instances such as the above are not uncommon:

The very strong message that NCOSS gets from the Aged Care Alliance consumer groups is that the complaints mechanism is not accessible to people and not responsive. There are some disjoints between making a complaint, how that goes through the scheme, whether or not it gets to the agency...and then how that is enacted.¹¹⁸

3.140 The Aged Care Lobby Group argued that family members have given up complaining to the CRS because the overall impression is that 'their complaints are trivialised or are made by an over-fussy, neurotic or guilt-ridden family member'. The Group also complained that anonymous complaints are not treated as seriously as other complaints.¹¹⁹ DoHA conceded that due to the nature of these complaints there can be no ongoing two-way communication with the complainant to provide feedback about their complaint, although they may be used to illustrate in a general sense particular problems.¹²⁰

3.141 Evidence suggests that complainants have difficulty getting complaints accepted by the CRS. Submissions noted that complaints made to the CRS have not been accepted because documentation and staff reports have not been available to substantiate a breach of standards.¹²¹ The CRS can accept complaints about any aspect of aged care which may be a breach of an approved providers responsibilities under the Aged Care Act. The Commissioner of Complaints noted that a preliminary assessment of a complaint is made to determine whether or not the complaint is to be accepted. This assessment is made on the information available and a complaint is accepted only if 'sufficient information' is provided in relation to the complaint.

117 *Committee Hansard* 11.3.05, p.59 (Mrs J Ma).

118 *Committee Hansard* 11.3.05, p.60 (NCOSS).

119 *Submission* 198, p.2 (Aged Care Lobby Group). See also *Committee Hansard* 22.2.05, p.31 (Aged Care Lobby Group).

120 *Submission* 191, Supplementary Information, 26.5.05 (DoHA).

121 *Submission* 158, p.2 (Advocacy Tasmania).

Moreover, the CRS must be satisfied that accepting the issue as a formal complaint is the best way to handle the problem.¹²²

3.142 Advocacy Tasmania explained this process and the frustration that it causes complainants:

The process is that they will then take the complaint to the home and there will be an investigation. Because there is an allegation, there is not automatically a complaint in a technical sense. That whole thing does not make any sense to consumers – if you have a complaint, it is a complaint – and it is very difficult to explain that technicality to people. So they go along and investigate what has been said. Of course they go to the home and ask about the incident and they look in the documentation....It boils down to one person's word against another, and because nothing in the documentation seems to suggest that this [incident] happened then there is no complaint. The complainer is told, 'Sorry, your complaint is not accepted'.¹²³

3.143 Evidence suggests that the number of complaints would be considerably higher if the CRS did not use such strict criteria for accepting complaints – in effect the CRS 'culls' the number of potential complaints. This also has the effect of discouraging many potential complainants from making complaints.

3.144 As noted above, some 13 per cent of all complaints lodged in 2003-04 were not accepted by the Scheme. The rate of non-acceptance of complaints was 33 per cent in the Northern Territory, 31 per cent in Tasmania, 26 per cent in Victoria, 8.5 per cent in Western Australia, 5.2 per cent in the ACT, 3 per cent in NSW and 1.9 per cent in South Australia. In Queensland all complaints lodged were accepted.¹²⁴

3.145 Witnesses also expressed dissatisfaction with the mediation process arguing that in many instances it is difficult to mediate, especially when serious incidents are involved, and often complainants are not given sufficient support.

...you cannot mediate about some things. It depends on the actual incident that has happened...Mediation is fine if there has been some behaviour – [for example] someone being nasty. Ideally it should be recognised that that did happen and there should be some acknowledgment of the fact that it happened...mediation is not always satisfactory, and unless people are supported it can be extremely intimidating.¹²⁵

122 Commissioner for Complaints, *Annual Report*, p.30.

123 *Committee Hansard* 28.4.05, pp.4-5 (Advocacy Tasmania).

124 Commissioner for Complaints, *Annual Report*, p.31.

125 *Committee Hansard* 28.4.05, p.5 (Advocacy Tasmania).

It is rather difficult to mediate with your jailors. If the climate in a particular home is more concerned with matters other than the care of the elderly then it is very hard to bring about change.¹²⁶

3.146 Submissions also argued that complaints about care are not necessarily passed on to the Agency by the Scheme unless they are serious or relate to a facility about which persistent complaints have been received.¹²⁷ DoHA noted, however, that all complaints are passed on to the Agency some individually, in the case of serious complaints, and others collectively in the sense that they may indicate broader trends or problems within facilities.

3.147 Submissions pointed to the need for whistleblower protection so that staff can report inadequate standards of care without fear of reprisal.¹²⁸ The ACT Disability, Aged & Carer Advocacy Service (ADACAS) noted that many complaints schemes and similar bodies charged with the investigation of community concerns include protection for people who reveal information which identifies deficiencies in systems, or alleged criminal activity by individuals.¹²⁹

3.148 Concern was also expressed about the apparent overlap of complaints schemes and the feeling that complainants are 'shunted' from one agency to another. As one witness noted:

In our case we have exercised all available complaints processes at state and Commonwealth levels about the serious situation of poor care and abuse. Two years after the completion of those processes our situation is actually worse than when we began. So we think our case is valuable in the sense that we are a rare test case of just how well the current system works.¹³⁰

Independent complaints agency

3.149 A number of submissions argued that due to the inadequacies of the CRS an independent complaints agency should be established. NCOSS argued that such an agency should:

- provide an accessible avenue for complaints and identify sector trends;
- report publicly and use transparent and independent processes;
- respond to the specific needs of people from culturally and linguistically diverse backgrounds and Indigenous Australians;

126 *Committee Hansard* 22.2.05, p.33 (Aged Care Lobby Group).

127 *Submission* 198, p.2 (Aged Care Lobby Group).

128 *Submission* 198, pp.2-3 (Aged Care Lobby Group).

129 *Submission* 167, Supplementary Information, 7.2.05 (ADACAS).

130 *Committee Hansard* 11.3.05, p.73 (Mr C Way). See also *Submissions* 211, p.3 (Dr N Duncan); 237 (Mr E Saul).

- involve independent advocacy at individual and systemic levels; and
- establish a transparent relationship with the Agency.¹³¹

3.150 The LHMU argued that an aged care ombudsman should be established to provide transparency and accountability in the management of complaints. The ombudsman would also have a role in educating residents, families and the broader community about the rights of older Australians receiving aged care services.¹³²

Conclusion

3.151 Evidence to the inquiry suggests that there are deficiencies with the operation of the Complaints Resolution Scheme. Concerns were expressed that the Scheme is not accessible nor sufficiently responsive to the needs of consumers, and the complaints mechanisms are unclear, unnecessarily complex and in some cases complaints are actively discouraged. The relatively high non-acceptance of complaints by the Scheme would indicate that there are grounds for concern.

3.152 While some evidence argued that an independent complaints agency should be established to improve the transparency and accountability of the complaints mechanism the Committee is not convinced that such an agency would necessarily address the concerns raised during the inquiry. The Committee therefore favours a reform of the current arrangements.

3.153 The Committee also considers that whistleblower legislation is required for those people wishing to disclose inadequate standards of care in aged care facilities.

Recommendation 16

3.154 That the Commonwealth review the operations of the Aged Care Complaints Resolution Scheme to ensure that the Scheme:

- **is accessible and responsive to complainants;**
- **provides for a relaxation of the strict eligibility criteria for accepting complaints;**
- **registers all complaints as a complaint, with the complaints being categorised by their degree of severity, such as moderate level of complaint, complaints where mediation is required or where more significant levels of intervention are required; and**
- **provides that the mediation process is responsive and open and that sufficient support for complainants is provided in this process.**

131 *Submission 204*, p.5 (NCOSS). See also *Submission 203*, pp.6-7 (NSW Aged Care Alliance).

132 *Submission 124*, p.20 (LHMU).

Recommendation 17

3.155 That the Commonwealth examine the feasibility of introducing whistleblower legislation to provide protection for people, especially staff of aged care facilities, disclosing allegations of inadequate standards of care or other deficiencies in aged care facilities.

Retribution

3.156 Evidence was presented during the inquiry detailing the fear of, or instances of, actual retribution and intimidation of residents and/or their families if residents or their families complained about conditions in homes or the quality of care. One submission noted that 'the scope of the issue is difficult to determine. Its very existence means people are afraid to report it, disclosing it only when they feel safe to do so. They may remain silent, even though significant efforts are made...to inform people of their right to complain'.¹³³ Information indicated that retribution or threats could occur in a number of situations, for example, staff against residents, management against residents or management against staff.

3.157 The types of retribution of residents are varied and include:

- being embarrassed or humiliated in front of other people;
- being forced to conform to routines;
- being called a 'dobber' if they complain;
- not encouraged to participate in activities;
- not being allowed to sit with friends at the lunch table;
- having personal items removed from their rooms;
- staff becoming less friendly, more formal with the resident;
- being shouted at and abused by staff; and
- any form of bullying or harassment.¹³⁴

3.158 Some indication of the extent of retribution was provided during the inquiry. In the ACT, the Disability, Aged & Carer Advocacy Service (ADACAS) reported 55 instances of actual retribution in aged care facilities from 2001-2004. Of the 23 homes in the ACT retribution was reported in 13 homes – almost half of all homes in the ACT. In nine homes the retribution reportedly came from management; in six it came from staff and in two it came from both management and staff. In five homes the number of reported cases of actual retribution was high, ranging from four to 10 cases. In the other nine homes, the number of cases ranged from one to three instances.¹³⁵ In

133 *Submission 167*, Supplementary Information, 7.2.05 (ADACAS).

134 See, for example, *Submission 167*, Supplementary Information, 7.2.05 (ADACAS).

135 *Submission 167*, Supplementary Information, 1.4.05 (ADACAS). See also *Committee Hansard* 11.2.05, pp.62-68 (ADACAS).

relation to the ACT, in 2003-04, the CRS dealt with four cases which raised the issue of real or potential retribution. All four of these complaints have been finalised.¹³⁶

3.159 The Committee questioned the Service as to whether retribution was part of an entrenched management culture in the aged care industry. The Service stated that this was not the case adding that where management is involved in cases of retribution – 'I would see that as a systemic issue within those particular homes. The others may be isolated'.¹³⁷

3.160 The Committee pursued this issue during the hearings in other States. In South Australia, the Aged Rights Advocacy Service stated that it provides advocacy services to an average of 800 people per year through its residential care program with another 300 people seeking information about their rights as consumers. Retribution or fear of retribution is raised in approximately 15-20 percent of these contacts.¹³⁸ The Aged Care Lobby Group in South Australia also noted that 'fear of reprisal and victimisation is a very real fear in nursing homes, particularly in smaller ones owned by some of the private providers'.¹³⁹

3.161 Advocacy Tasmania noted that it only receives 'a handful of actual instances of retribution' a year, but added that this 'is not the same as the number of people who fear retribution'.¹⁴⁰ The group also noted that residents and family members often fear retribution if they speak to assessors with concerns during accreditation visits.¹⁴¹

3.162 ADACAS stated that all State and Territory advocacy groups have reported to the Service instances of actual retribution in their respective jurisdictions.¹⁴²

3.163 The CPSA stated that the low proportion of complaints to the CRS by residents compared with relatives 'does indicate that intimidation could be a factor' – 'nursing home residents have to put up with any possible retribution. Relatives do not'.¹⁴³

3.164 The issue of retribution in aged care facilities was highlighted by the Commissioner for Complaints in a recent annual report.

Many discussions with relatives and friends of care recipients reveal an obvious and pervasive attitude – one where there is an expressed anxiety

136 *Submission* 191, Supplementary Information, 26.5.05 (DoHA).

137 *Committee Hansard* 11.2.05, p.64 (ADACAS).

138 Cited in *Submission* 167, Supplementary Information, 1.4.05 (ADACAS).

139 *Committee Hansard* 2.2.05, p.29 (Aged Care Lobby Group).

140 *Committee Hansard* 28.4.05, p.15 (Advocacy Tasmania).

141 *Submission* 158, p.2 (Advocacy Tasmania).

142 *Submission* 167, Supplementary Information, 1.4.05 (ADACAS).

143 *Submission* 79, p.8 (CPSA).

not to make a fuss, not to complain, not to inquire too often and not to be noticed for fear that it would reflect badly on their relative and lead to some kind of retribution.¹⁴⁴

3.165 While advocacy and other groups argued that retribution is a problem in nursing homes, providers and unions representing workers in the aged care sector suggested that it is not a significant issue, although the fear of retribution may be an issue.

3.166 The ANF stated that the issue 'is not something that we would ever condone at all and it has come up from time to time. Sometimes it is more a fear than something that actually happens' but the union stated that it was not a significant problem in aged care facilities.¹⁴⁵ The ANF submitted that it was not raised in recent phone-in surveys in relation to issues in aged care nor in surveys conducted in the union's journal. The AMA also indicated that it was not aware of any reports of intimidation of residents or their families made to its members.¹⁴⁶

3.167 Providers indicated that they were not aware of retribution being a significant problem in homes. A representative of ACSA noted:

...I have heard no instance of bullying or intimidation by providers of residents or their families...I meet quite regularly with the residents' rights association. We sit on the same committees and so on. No-one has raised that issue with me.¹⁴⁷

3.168 One provider noted that residents 'may have a fear of retribution and it would never be actualised, but the fear is enough if you are on your own and do not have a choice. The biggest challenge is really creating an environment for people to feel safe to raise the point'.¹⁴⁸ Another provider noted that 'we would love to think that we could eliminate that perceived fear. Certainly, I am not aware that anybody would actively pursue that sort of retribution. We are very aware, and want to act immediately, if there is any suggestion that any of our staff may be acting inappropriately in how they care for and respond to the care needs of a resident'.¹⁴⁹

3.169 Advocacy groups stated, nevertheless, that there needs to be an investigation to identify the actual level of retribution in aged care homes. The groups also proposed that a national strategy for the elimination of retribution, and fear of retribution in aged care facilities, should be implemented involving all stakeholders. ADACAS noted that a national strategy should identify and trial ways of eliminating

144 Commissioner for Complaints, *Annual Report 2002-03*, p.29.

145 *Committee Hansard* 11.2.05, p.46 (ANF).

146 *Committee Hansard* 11.2.05, p.26 (AMA).

147 *Committee Hansard* 26.4.05, p.19 (ACSA).

148 *Committee Hansard* 23, 2.05, p.32 (Silver Chain).

149 *Committee Hansard* 23.2.05, p.32 (Baptistcare).

the fear of retribution and identify and implement ways to eliminate actual retribution.¹⁵⁰

3.170 DoHA advised the Committee that the Department and the Commissioner for Complaints have met with ADACAS to seek their views on options for addressing the issues of actual and perceived fear of retribution. Since then the Department has sought and received feedback from ACT-based homes. The Commissioner for Complaints has also undertaken a project to review available literature and evidence and identify strategies that could be considered; and in May 2005 the Aged Care Advisory Committee, the major forum for consultation with the aged care sector, considered these issues – industry groups have agreed to consider specific initiatives to address both any incidence and perceptions around this issue in aged care homes.¹⁵¹

Conclusion

3.171 Evidence to the Committee pointed to instances of retribution and intimidation of residents in aged care facilities and their families across many States. The Committee found this evidence particularly disturbing and reprehensible as these practices prey on particularly vulnerable people and cause obvious concern to the families of residents some of whom may themselves be victims of intimidation.

3.172 The Committee was unable to form a view as to the possible extent of the problem. The Committee believes, however, that there needs to be a comprehensive investigation of this issue to determine how widespread it is and the extent to which it represents an entrenched culture in aged care facilities or sectors of the industry. The Committee believes that the review should also examine the feasibility of introducing a national plan of action to address this issue should the problem be found to be extensive across the industry.

Recommendation 18

3.173 That the Commissioner for Complaints conduct an investigation into the nature and extent of retribution and intimidation of residents in aged care facilities and their families, including the need for a national strategy to address this issue.

Promoting education and training

3.174 One of the functions of the Agency is to promote high quality care, and assist the industry to improve service quality, by identifying best practice and providing information, education and training to the industry. The Agency's underlying philosophy for education is that high quality care will be promoted through a

150 *Submission* 167, Supplementary Information, 7.2.05 (ADACAS).

151 *Submission* 191, Supplementary Information, 26.5.05 (DoHA).

combination of education and accreditation activities – 'neither strategy alone will bring about sustained improvement in the sector'.¹⁵²

Promoting best practice

3.175 The Agency seeks to promote best practice through a number of means, including:

- internal identification of best practice – Agency assessors report examples of better practice and where the Agency considers the practice warrants wider distribution, the provider is contacted.
- articles in the Agency's quarterly newsletter, *The Standard*, on better practice – the Agency's publication regularly showcases facilities willing to share their better practice systems and processes.
- Better Practice events – programs on better practice have been held in several capital cities and other centres.
- Better Practice compendium – the compendium showcases some of the homes that achieve an Agency higher award.
- Higher awards – homes achieving a higher award are showcased on the Agency website.¹⁵³

3.176 The Agency's efforts to promote best practice have been generally viewed favourably. One witness commented that the Better Practice events have been seen 'in a very positive light' by participants.¹⁵⁴ One industry peak body noted, however, that the seminars did not involve formal consultation with the industry, but relied on the practices demonstrated by those facilities which had been awarded meritorious or commendable ratings by the Agency.¹⁵⁵

3.177 Some areas for improvement were, however, suggested. CHA argued that the Agency should develop a standard evidence-based approach to defining what is actually 'best practice' in aged care.¹⁵⁶ Blue Care argued that the showcasing of best practice initiatives should be an ongoing process rather than at the end of an extensive round of accreditation.¹⁵⁷ UnitingCare Australia argued that the Agency should provide aggregated information about the best approaches to improving the quality of service provision in facilities. While facilities seek to continuously improve standards, improved access to annual comparative information on successful ways of operating

152 *Submission* 105, p.11 (ACSAA).

153 *Submission* 105, p.11 (ACSAA).

154 *Committee Hansard* 26.4.05, p.22 (VAHEC). See also *Submission* 166, p.8 (CHA).

155 *Submission* 170, p.11 (ACS of NSW & ACT).

156 *Submission* 166, p.9 (CHA).

157 *Submission* 116, p.4 (Blue Care).

would be helpful.¹⁵⁸ Benetas noted that the identification of best practice by the Agency remains 'elusive' but inroads are being made through evidence based practice and other key initiatives.¹⁵⁹

Education and training

3.178 The Agency provides a number of education and training initiatives. These include:

- Seminar series – the Agency conducted a seminar series for the industry *Turning Data into Action* in 2003. Some 68 seminars were conducted in capital cities and rural and regional areas, with 1507 participants attending.
- Self-directed learning packages – these packages, on the Agency web-site, cover self assessment, continuous improvement and data and measurement issues.
- Assessor and provider resource material – the *Audit Handbook for Quality Assessors* and *Results and processes in relation to the expected outcomes of the Accreditation Standard* handbook are available on the Agency web-site. These provide information about the Accreditation Standards and how the assessments are undertaken.
- Agency newsletter – the Agency's newsletter, *The Standard*, is distributed nationally to industry and other stakeholders.
- Education during support visits – education sessions are available – delivered by trained Agency staff – as part of support contact arrangements.
- Satellite television – the Agency is conducting a pilot to evaluate the use of satellite television as a medium for delivering training particularly to remote sites.
- Consumer education – the Agency conducted 40 information sessions directed at residents and relatives across Australia in 2004. Some 1169 people attended these sessions.
- Presentations at industry conferences.¹⁶⁰

3.179 The Committee received a variety of views on the appropriateness of the Agency's education and training role. Some provider peak bodies noted that there was a potential conflict of interest in the Agency's dual roles of monitoring compliance in addition to promoting quality improvement.

158 *Submission 57*, p.7 (UnitingCare Australia).

159 *Submission 73*, p.2 (Benetas).

160 *Submission 105*, pp.12-13 (ACSAA).

3.180 ANHECA noted that:

...[we] see no difficulty with an agency that purely has quality improvement as its objective, undertaking this role. However, an organisation that also has a large compliance role is not able to effectively do this as the industry will not seek advice and support from an organisation, that the next day can be 'inspecting' its services and ensuring compliance.¹⁶¹

3.181 ACS of NSW & ACT also noted that education is not the Agency's core business and there are other better qualified organisations which could fulfil this role for the industry.¹⁶²

3.182 The Hogan Review also argued that the role of the Agency should be directed primarily to accreditation services and the dissemination of accreditation results. The review questioned the expansion of the Agency's education role to compete in areas of staff training where there are other competent providers. The review also questioned the appropriateness of an agency tasked with evaluating performance also being a major source of training relating to performance.¹⁶³

3.183 Other provider peak bodies, however, supported the Agency's education role. CHA argued that if the Agency took on a purely 'policeman' role it would create a 'them and us' situation between the Agency which would be counter-productive. CHA added that:

The Agency gains a significant amount of information from the auditing and compliance processes. Sharing this information is a valuable way for the industry to learn about 'best practice' in quality management and to gain from their peers.¹⁶⁴

3.184 CHA in a survey of its members found that they rated the education and training role of the Agency as generally favourable. Some respondents, however, expressed the view that that the Agency needs to be more proactive with an education process that reflects industry issues. They felt that education and training is irregular and not readily accessible. Others considered that the education packages produced by the Agency are comprehensive but an ongoing program of training in their use would be beneficial. While the packages are available on the website, not everyone has access to the internet and in some cases facilities were unaware of the packages' existence.¹⁶⁵

161 *Submission 74*, p.10 (ANHECA). See also *Submission 196*, p.5 (Aged Care Qld).

162 *Submission 170*, pp.10-11 (ACS of NSW & ACT).

163 Hogan Review, p.243.

164 *Submission 166*, p.7 (CHA).

165 *Submission 166*, pp.7-8 (CHA).

3.185 While ACSA in its submission to the inquiry noted that, while the Agency operates as a monopoly, it would be better to confine its education and training role to ensuring that the industry is fully informed about the accreditation system, in oral evidence the organisation indicated that it was not opposed to the Agency providing training courses.¹⁶⁶ ACSA stated that:

...[we] have got no objection to it being a participant in that marketplace for the provision of quality training but I think it needs to be careful not to overuse its strong position in that regard...They are a legitimate player but by no means the only one.¹⁶⁷

Conclusion

3.186 The Committee believes that the Agency has a legitimate role in promoting 'best practice' throughout the industry. The Committee considers that the Agency's involvement in these activities can assist in the promotion of high quality care in aged care facilities. The Committee believes, however, that the Agency should not have a direct role in staff training due to the potential conflict of interest that that involves.

Recommendation 19

3.187 That the Agency's role in promoting 'best practice' continue and that it:

- **develop a standard evidence-based approach to defining 'best practice' in aged care; and**
- **provide regular aggregated information to the industry on methods for achieving 'best practice' in the provision of aged care services.**

The Committee further recommends that the Agency consider ceasing its direct role in providing direct staff training given the potential conflict of interest that this entails.

Reducing excessive documentation

3.188 Evidence to the inquiry, especially from providers and unions with staff employed in the aged care sector, complained of the excessive administrative and paperwork demands placed on staff as a result of accreditation and the requirements of the RCS.

3.189 ANHECA noted that:

...the current accreditation system does [not] in any way assist the sector to reduce administrative and paperwork demands on staff, in fact, the reverse. Because the Agency is so focused on the minutia of day to day activities and not on systems improvement, it is forcing residential aged care

166 *Submission 173*, p.4 (ACSA).

167 *Committee Hansard 26.4.05*, p.2 (ACSA).

providers to focus on forms and ticking of boxes, rather than ensuring that the quality systems work effectively for overall service improvement.¹⁶⁸

3.190 The Royal College of Nursing, Australia (RCNA) noted that its members:

...have expressed their frustration at the huge amount of documentation required by the accreditation process and the increasing amount of time they have to spend on paperwork to meet accreditation requirements instead of providing hands-on nursing care.¹⁶⁹

3.191 The HSU noted that members consistently express concern about the amount of documentation required of them.¹⁷⁰ The LHMU also noted that 'paperwork is one of the largest barriers to the direct delivery of care. It is also one of the largest frustrations of those that work in aged care'.¹⁷¹ The Nurses Board of WA noted that the administrative and paperwork demands 'have a real cost in dollar terms and a cost on the emotional and morale demands on staff'.¹⁷²

3.192 The Agency, responding to these concerns, stated that that it does not expect homes to create paperwork or documentation other than the accreditation application. For most homes this requirement falls only once every three years. The Agency stated that the application form has recently been simplified following consultation with the industry.

The assessment process seeks evidence of compliance with the Accreditation Standards. Agency assessors have no expectation to see any more documentation than that which would exist within a quality management framework.¹⁷³

3.193 The documentation required for accreditation, *Application for Accreditation*, consists of a 49 page document. The main part of the document consists of a 'self-assessment' section which consists of blank pages where the provider is required to provide information that demonstrates that the provider has achieved the Expected Outcomes of the various Accreditation Standards.¹⁷⁴

3.194 The Agency noted that the accreditation application information and forms are available on-line on its website. The Agency encourages all homes to apply for their accreditation on-line. A version is also available on CD. A printed version is also available for those unable to access a computer or have difficulty down-loading a

168 *Submission 74*, p.10 (ANHECA).

169 *Submission 71*, p.4 (RCNA). See also *Submission 201*, p.22 (ANF).

170 *Submission 59*, p.11 (HSU - NSW Branch).

171 *Submission 124*, p.18 (LHMU).

172 *Submission 89*, p.3 (Nurses Board of WA).

173 *Submission 105*, p.14 (ACSAA).

174 The *Application for Accreditation* may be accessed at www.accreditation.aust.com

printed version, or who would prefer to fill in a printed application rather than on-line.¹⁷⁵

3.195 Some groups were of the view that the documentation requirements are not excessive. Geriaction noted that aged care services with well established quality management systems 'do not find the administrative requirements of the three year accreditation application onerous'. Geriaction noted, however, that there may be opportunities for refining processes related to the accreditation of newly established or restructured services to minimise paperwork demands on staff.¹⁷⁶ The Victorian Branch of the ANF also commented that the accreditation paperwork was not 'overly burdensome compared to other such systems'.¹⁷⁷

3.196 Throughout its hearings the Committee pressed groups concerned about excessive documentation to be specific as to what documentation they considered was not required. Some suggestions to reduce the amount of paperwork required were made during the inquiry. Some witnesses suggested the interRAI (Resident Assessment Instrument) as a useful model. The interRAI series of assessment protocols consist of a series of data items that constitute a clinical assessment. One witness stated that the Instrument:

...will effectively reduce paperwork...Currently, in order to substantiate our funding, we are required to generate very text-driven documentation...what is being proposed...it is almost like a tick system, I guess. It is a very prescriptive set of assessment documents.¹⁷⁸

3.197 The Australian Society for Geriatric Medicine suggested that systems such as the internationally benchmarked interRAI Instrument 'may appear complex when first examined, but in the long run are the most efficient since they achieve the desired outcomes'.¹⁷⁹

3.198 CHA noted that some of its members argued that provision of an annual summary of activities to the Agency would reduce the three year 'panic' when the audit time comes around again.¹⁸⁰ The RCNA suggested that the Agency should further refine the Accreditation Kit to reduce unnecessary repetition between visits; and not require already accredited facilities to complete the full version of the Kit – this should only be required of new services or those requiring improvements. The College also suggested that the dual system of accreditation should be abandoned for

175 *Submission* 105, Supplementary Information, 27.5.05 (ACSAA).

176 *Submission* 88, p.2 (Geriaction).

177 *Submission* 66, p.2 (ANF - Vic Branch).

178 *Committee Hansard* 28.4.05, p.39 (Mary Ogilvy Homes Society). See also *Committee Hansard* 27.4.05, pp.9,11-12 (Melbourne Citymission).

179 *Submission* 80, p.1 (ASGM).

180 *Submission* 166, p.8 (CHA).

facilities that are part of a larger organisation and undergo Australian Council on Healthcare Standards accreditation.¹⁸¹

3.199 The Committee examined the issues of reporting by exception and the increased use of IT as possible means of reducing the burden of excessive paperwork arising out of the accreditation process.

Reporting by exception

3.200 Reporting by exception was supported by a number of organisations. Aged Care Qld noted that:

We would certainly say that it would be helpful if more of the reporting could be done on an exception basis rather than having to tick the box every time you did something or write a comment every time, with every detail needing to be recorded.¹⁸²

3.201 The Nurses Board of WA also indicated its support noting that 'most documentation across all areas of health is by exception. Clearly if you have the care planning processes in place and the understanding of what is normal then exception reporting is by far the better approach'.¹⁸³

3.202 Witnesses noted, however, that the requirements of the accreditation process are a barrier to its introduction. Bennetas stated that it would take substantive change to the accreditation process for the system to be introduced.

At the moment we have a system where, if you cannot prove that you have provided care to a resident...you would not actually pass accreditation because you have no evidence to back up what you have done.¹⁸⁴

3.203 Another problem identified was that with a the high turnover of staff in many aged care facilities, especially agency staff or staff that work on a temporary or casual basis, there would need to be an effective system in place that records what tasks have and have not been performed. The Victorian Association of Health & Extended Care (VAHEC) noted that while reporting by exception could be introduced in a facility with regular staff – 'certainly staff turnover and the skills set of staff would be very important' in moving to this system.¹⁸⁵

181 *Submission 71*, p.5 (RCNA).

182 *Committee Hansard* 18.3.05, p.18 (Aged Care Qld). See also *Committee Hansard* 26.4.05, p.10 (ACSA).

183 *Committee Hansard* 23.2.05, p.18 (Nurses Board of WA). See also *Committee Hansard* 23.2.05, p.6 (Centre for Research into Aged Care Services).

184 *Committee Hansard* 27.4.05, p.4 (Benetas).

185 *Committee Hansard* 26.4.05, p.10 (VAHEC).

IT systems

3.204 The increased use of IT, including palm pilots and other systems, to reduce paperwork was also raised in evidence. Witnesses commented that such systems have the potential to free-up staff to devote more time to patient care.

If the format of the software was very much a click-and-flick type process...it would free up time for someone to be able to provide care to residents instead of sitting down with paper based systems and writing out in longhand what they had done that day.¹⁸⁶

3.205 Witnesses noted, however, that the underlying reporting systems would need to be compatible with any new IT system.

...even if you have a system that is electronic rather than paper based, unless the systems underlining that are streamlined it is not going to make it any easier...So, while there may be some gains...there has to be some underlying work to the reporting systems.¹⁸⁷

3.206 Aged Care Qld noted that there has been some resistance to utilising IT systems in the aged care sector – 'there is a fear that you might end up with a standard care plan produced by the system, not personalised enough for the person. So the system is producing a standard rather than the staff directing specific things for each resident'.¹⁸⁸

3.207 Witnesses argued that the level of investment in IT would need to be substantial. ACSA noted that there has not been any explicit investment in IT by 'any of the funding levels of government', in contrast with the acute health sector where there has been substantial government investment in such systems.¹⁸⁹ One provider submitted that at present the return on investment in IT 'would not be there in either efficiency or productivity, so we are reliant on a document system'.¹⁹⁰

3.208 DoHA is currently working with the aged care sector to develop an information management and communications technology framework that will support a planned and coordinated approach to the use of IT in the sector. The framework will incorporate outcomes from the Clinical IT in Aged Care project. This project is investigating how clinical IT applications or tools can support and improve care standards for residents in aged care homes. A series of projects are being funded to trial clinical IT tools or applications that are not currently in use in the sector to evaluate their ability to assist in the delivery of care for residents. The tools focus on point of care assistance and the increasing interrelationship between aged care and the

186 *Committee Hansard* 27.4.05, p.4 (Benetas).

187 *Committee Hansard* 26.4.05, p.11 (Victorian Healthcare Association).

188 *Committee Hansard* 18.3.05, p.18 (Aged Care Qld).

189 *Committee Hansard* 26.4.05, p.11 (ACSA).

190 *Committee Hansard* 27.4.05, p.4 (Benetas).

broader health sector, such as GPs and pharmacists. The projects include the use of computerised medication management in aged care facilities and electronic prescribing between homes and local GP practices.

3.209 The Department is also sponsoring a series of seminars around Australia to assist providers to better understand how IT and electronic commerce, if implemented appropriately, can improve the efficiency of aged care services. DoHA is also working on a project to develop electronic channels for submission of various aged care forms from facilities to the Department.¹⁹¹

Resident Classification Scale

3.210 The second area of concern relating to excessive documentation was with the paperwork required by the Resident Classification Scale (RCS).¹⁹² The RCS is a validation system which monitors and determines the care level classification – and thus the funding level – of residents in aged care facilities. Some submissions suggested that the documentation required of the RCS imposes greater paperwork demands on staff than accreditation paperwork requirements.¹⁹³

3.211 The RCS is to be replaced in 2006 with a new funding Instrument – the Aged Care Funding Instrument (ACFI). DoHA stated that the new funding assessment tool will improve the funding system so services will spend less time on paperwork and more time in providing care. The Department acknowledged that:

The existing RCS framework has become an administrative concern for aged care providers. RCS ratings that were originally intended to be drawn from existing care documentation developed by aged care homes to provide care for each resident have increasingly become a driver of care documentation rather than being a by-product of it.¹⁹⁴

3.212 DoHA stated that in contrast to the RCS, the ACFI:

- focuses on those areas of care that are the best predictors of differences in the relative cost of care, so it has fewer care domains than the RCS.
- is designed to measure the need for care, *not* the care provided (as supported by documentation) when determining funding.
- supports a different model of accountability for funding. The focus of the ACFI will be on the resident and on assessments of care need required by the ACFI rather than being based on the care plan and the on-going record of care delivery.¹⁹⁵

191 *Submission* 191, Supplementary Information, 20.6.05 (DoHA).

192 *Submissions* 201, p.22 (ANF); 179, p.6 (NSWNA).

193 *Submission* 66, p.2 (ANF - Vic Branch).

194 *Submission* 191, Supplementary Information, 20.5.05 (DoHA).

195 *Submission* 191, Supplementary Information, 29.5.05 (DoHA).

3.213 The ACFI will be tested in a national trial during 2005. The data collection of the national trial will be conducted during July and October 2005, followed by an assessment of the results. Data collected during the trial will allow a detailed analysis of the documentation burden of ACFI on assessors and aged care home staff.

3.214 The Committee welcomes the development of the ACFI, especially in its aim to reduce the paperwork burden on staff in aged care facilities, and looks forward to a successful outcome of the trial into the Instrument.

Conclusion

3.215 The Committee received evidence indicating that the administrative and paperwork demands in connection with accreditation and the RCS pose a considerable burden on providers and staff. Time spent complying with excessive paperwork was significantly affecting the time spent by staff in providing care. The Committee believes that the Agency should review its documentation requirements in relation to accreditation with a view to streamlining the paperwork requirements where possible without compromising the accountability requirements of providers. The Committee notes that the RCS is to be replaced in 2006 with a new funding Instrument with one of the aims of the new system being a reduction in paperwork for aged care services. The Committee supports this initiative.

3.216 The Committee also considers that the Agency should examine other possible options of reducing paperwork including reporting by exception. The Committee notes the current initiatives that the Department is undertaking in relation to the promotion of IT in the aged care sector and believes that such initiatives should be implemented as a matter of priority as another means of streamlining operations and reducing the paperwork burden on services and staff.

Recommendation 20

3.217 That the Agency, in consultation with industry stakeholders and consumers, review the information required to be provided in the document *Application for Accreditation* and consider the feasibility of other options such as reporting by exception, with a view to reducing superfluous and time consuming reporting.

Recommendation 21

3.218 The Committee welcomes the Commonwealth's initiatives in promoting IT in the aged care sector and recommends that the implementation of these initiatives, as well as increasing the take-up rate, should be a matter of priority.

CHAPTER 4

YOUNG PEOPLE IN RESIDENTIAL AGED CARE FACILITIES

These young people can't use a buzzer, can't shout out for attention and yes, we know that nursing homes are understaffed and aren't really set up for high maintenance care for these ABI patients but does that really explain the missed PEG feeds, the discarded dressings on the floor, the lack of cleanliness in the room or the horrendous bed sores that sometimes never heal. This is the cry for help of some of the most marginalised in our society today.¹

Introduction

4.1 In May 1990, this Committee reported on its inquiry into accommodation for people with disabilities.² The Committee found that it was not appropriate for young people to share accommodation, such as nursing homes, with older people and cited the recommendation of the 1986 Nursing Homes and Hostels Review:

More appropriate care services should be found as a matter of priority for younger people with disabilities in general purpose nursing homes predominantly for aged persons.³

4.2 Despite these recommendations, young people with disabilities are still accommodated in residential aged care facilities and the number has been increasing over the last decade. At the present time there are over 6000 young people (those aged under 65 years) in residential aged care facilities with the Committee hearing that in Victoria a nine year old is accommodated in an aged care facility.⁴ Many submissions noted that with improved medical outcomes for severe spinal and head injuries and other illnesses, more young people will be in need of care in the future. Very young people, even with severe disabilities, may have normal life expectancy and require support for 40 to 50 years. Some people with degenerative conditions, such as Huntington's Disease, may require complex medical care for ten or more years.

4.3 Another group of disabled people who will require care in the future are young people with disabilities being supported at home by ageing parents. In many instances these young people will require residential care, often when their parents

1 *Submission 123*, p.4 (Ms N Nicholson & Co-signatories).

2 Senate Standing Committee on Community Affairs, *Accommodation for People with Disabilities*, May 1990.

3 Department of Community Services, *Nursing homes and hostels review*, AGPS, 1986 cited in *Accommodation for People with Disabilities*, p.46.

4 *Committee Hansard 27.4.05*, p.66 (Aged Care Assessment Services Victoria).

become frail and/or infirm or when the level of home services available can no longer adequately meet their changing needs.⁵

4.4 While witnesses stated that aged care facilities were not appropriate for young people, they access this form of accommodation because there are no reliable alternative options. The Young People in Aged Care Alliance (YPACA) stated:

In fact, nursing homes are perceived as 'dumping grounds' for people that the system has given up on and, while these options remain, all people with existing disabilities or newly acquired disabilities are potentially at risk.⁶

4.5 Aged care providers were also concerned that young people are placed in their facilities as the needs of the frail aged and young disabled 'couldn't be more diverse and both groups suffer to a greater or lesser extent'.⁷ The parent of a 24 year old currently residing in an aged care facility stated:

Staffing levels in the Aged Care Facility may be consistent with care for people in the end stages of life, but they are nowhere near to being adequate for the different and more intense needs of young people with complex care needs.⁸

4.6 The Office of the Public Advocate Victoria also noted that:

The younger cohort is likely to have a significant representation of high level care needs. This group includes young people physically incapacitated through road and other trauma. There are a proportion of people with an Acquired Brain Injury (ABI) as a consequence of alcohol misuse and trauma. There are also people experiencing the degenerative effects of specific medical conditions such as Multiple Sclerosis (MS) and Huntington's disease. The group is therefore likely to represent a broader and at times more complex range of care issues than older people who are more likely to have similar disabilities such as dementia and age related frailty. As a consequence this group of people represents particular challenges in devising accommodation options that can meet both their physical care and psycho-social needs.⁹

4.7 This chapter looks at the issues surrounding the accommodation of young disabled people in aged care facilities as well as the provision of services for those living in the community.

5 *Submission 51*, p.1 (Royal District Nursing Service).

6 *Submission 56*, p.2 (YPACA).

7 *Submission 8*, p.3 (Horton House).

8 *Submission 9*, p.2 (Ms G Foy).

9 *Submission 121*, p.4 (Office of the Public Advocate, Victoria).

The number of young people in aged care facilities

4.8 Young people enter aged care facilities because of disabilities arising from a variety of reasons including Acquired Brain Injury (ABI), Motor Neurone Disease (MND), Multiple Sclerosis (MS), malignant brain tumour or Cerebral Palsy. Data provided by the Department of Family and Community Services (FaCS) indicate that the number of young people aged under 50 in residential aged care in May 2005 is less than in July 2002, decreasing from 1075 to 1007 (this latter figure does not include a small number in the ACT). During this time, the number aged under 65 years increased from 5994 to 6398.¹⁰ The National Alliance of Young People in Nursing Homes (NAYPINH) stated that in early 2004 there was a 'spike' in numbers entering nursing homes with an additional 73 young people accommodated in aged care facilities between January and March 2004.¹¹

Table 4.1: Number of persons aged under 65 years in residential aged care facilities as at May 2005

State	0-49 yrs	50-59 yrs	60-64 yrs	Total
NSW	399	955	955	2 309
VIC	214	655	663	1 532
QLD	228	591	528	1 347
SA	71	188	208	467
WA	60	197	216	473
TAS	21	71	67	159
NT	14	31	21	66
ACT	X	17	28	45
AUSTRALIA	1 007*	2 705	2 686	6 398*

Note: The small number of residents in the ACT makes them potentially identifiable. These figures have been suppressed to protect the privacy of the individuals concerned.

* Totals do not include the small number of residents in the ACT.

Source: DoHA, *Submission 168*, Additional Information 20.6.05 (FaCS).

4.9 A more detailed analysis of young people in aged care facilities is difficult to obtain. NAYPINH stated that 'it is very difficult to know what type of disability young people already in aged care facility have because the Department of Health and

¹⁰ *Submission 168*, p.2, Additional Information 20.6.05 (FaCS).

¹¹ *Submission 160*, p.6 (NAYPINH).

Ageing does not collect data according to disability type, just according to location and age ranges'.¹² However, some indicative information was provided to the Committee. NAYPNH cited the following breakdown of young people in aged care facilities:

- Acquired Brain Injury (ABI) 30%
- Physical Disability 27%
- Neurological 23%
- Intellectual/psychiatric 20%¹³

4.10 Individual organisations also provided information. The Multiple Sclerosis (MS) Society of NSW stated that there were 100 people under the age of 60 years with MS in aged care facilities in NSW.¹⁴

4.11 There are 6.5 cases of Huntington's Disease (HD) per 100 000 of population. In NSW there are around 400 people at any one time with HD. The Australian Huntington's Disease Association NSW stated that in 2002 there were 75 people under 65 years with HD in residential care. Of these, 31 aged under 50 years were in residential care with 23 in nursing home, and 8 in hostels; 33 aged between 50 and 60 years were in residential care with 27 in nursing homes, 3 in hostels and one in a psychiatric hospital and 2 others in care but the level not known.¹⁵

4.12 The number of young people who are either in acute care hospital beds or in the community who are viewed as 'at risk' of entering aged care facilities is unknown. However, the MS Society of NSW indicated that there were approximately 300 people in New South Wales who MS Society outreach workers have identified as being at immediate risk of being admitted to aged care facilities if there is even a slight change to their current support systems.¹⁶

4.13 NAYPINH predicted that there will be 10 000 young people in nursing homes by 2007 if the current trends continue and stated that 'the current rate of entry for young people at the moment is a young person entering an aged care facility somewhere in Australia every day of the week'.¹⁷

12 *Committee Hansard* 26.4.05, pp.70-71 (NAYPINH).

13 *Submission* 160, p.5 (NAYPINH).

14 *Submission* 69, p.2 (MS Society of NSW).

15 *Submission* 63, p.4 (Australian HD Association (NSW)).

16 *Committee Hansard* 19.8.04, p.1 (MS Society of NSW).

17 *Committee Hansard*, 26.4.05, p.56 (NAYPINH).

Younger people with disabilities in the community

4.14 As well as evidence about young people already living in aged care facilities, much evidence was received by the Committee concerning people with disabilities living in the community who face the prospect of becoming residents in aged care facilities because no other suitable accommodation is available. As noted above, it is not known how many people may fall into this category but a number of groups at risk were identified including those people who are cared for by ageing parents and those whose medical needs cannot be supported by community based services.

Ageing carers

4.15 Many ageing carers have provided care for family members for years, if not decades. This length of caring takes its toll on ageing carers: physically, financially, socially and emotionally. At a time when others have enjoyed a long retirement, carers face the anxiety of what will happen to their children once they require aged care. For many people with a disability, and indeed their carers, one of their biggest fears is that if community services are unavailable, there will be no option but to enter a nursing home. One parent told the Committee:

Probably the most important thing that I would like to mention today is our fear for the future. While we love looking after Paul at home, we will not always be here to do this. I am terrified about what will happen to Paul after we have gone. I would never expect my other children to take over this responsibility. They deserve a life of their own. There has to be somewhere in the future for our young people to be accommodated for either respite or long-term care. This problem affects us all: it is our kids that we are talking about, and it could happen to anybody's family. I really hope and pray that things will change for the better in the future.¹⁸

Case study – UnitingCare network

This week the parents of a young man of 48 approached our network. This man, who has an intellectual impairment, was admitted to hospital. He now requires constant attention for feeding and toileting which his parents, 70 and 75, cannot do, being themselves too frail to get him out of bed and too tired after years of supporting him to motivate him into doing even the simplest things – like sitting up – for himself. The hospital wanted him to go home. No supported accommodation was available – the only option for this young man was a residential aged care facility.

Submission 57, p.8 (UnitingCare).

4.16 In November 2004, the Minister for Family and Community Services announced that State and Territory Community and Disability Services Ministers had

18 *Committee Hansard* 26.4.05, p.28 (Mrs V Fear).

accepted a plan to help ageing carers of disabled children. A working party of officials is to provide advice as to the steps governments will take to:

- consult with older carers of people with disabilities to understand the present unmet needs for support and future needs for care of their sons and daughters;
- provide more transparent planning for future service provision and allocation of resources;
- provide greater confidence amongst older carers that, with cooperation between the Australian, and State and Territory Governments, the needs of their sons and daughters will be better met; and
- enable increased personal/family provision for future care.

4.17 The Ministers also agreed to negotiate with the Commonwealth on mutually acceptable arrangements to meet the respite needs of carers over 70 years of age. The Commonwealth has allocated \$72.5 million over four years for respite for older parents caring for children with a disability, subject to it being matched by State and Territory Governments.¹⁹

Living in the community with disabilities

4.18 There are many people with severe disabilities who live at home. They do so with the help of family members and government and community funded support services. The Committee was provided with many cases where families have gone to extraordinary lengths to support their family members at home.

4.19 The burden on carers can be extremely high and carers may also have the additional responsibilities of raising the family as well as being the bread winner. Some children take on the role of carer for their affected single parent or when the healthy parent is working. In the case of inherited diseases the Committee heard that it is not uncommon to see some carers who care for more than one family member or may be at risk themselves. A practitioner stated that one person reported caring for family members for 30 years: affected spouse and several affected adult children all under the age of 65 years.²⁰

4.20 The impact of chronic illness and the stress of care on families are considerable. Support groups noted that marriage breakdowns were not uncommon and this further exacerbated the care and accommodation needs of disabled people. The Cerebral Palsy League of Queensland indicated that family breakdown sometimes resulted in children being placed in aged care facilities:

...the reason sometimes children with disabilities end up living in nursing homes is that there is a family breakdown because of the high support needs

19 Senator the Hon Kay Patterson, Minister for Family and Community Services, 'Ministers agree to explore options for succession planning for older carers', *Media Release*, 26.11.04.

20 *Submission 24*, p.2 (Dr E McCusker).

around the child. They just cannot cope. They cannot get enough support when the child is younger and then as the child gets beyond adolescence they grow heavy to lift and some of those sorts of things occur. They do not have enough support and there is a lot of stress put on the family unit.²¹

Crying out for help

I am a 46 year old mother. He is 21 years old now. He was 17 when he got severe hypoxic brain injury while he was depressed. I am really tired. My husband and I are both worn out over this past 3½ years. My son is only 21. He needs the stimulation of young people. He loves older people but he is not old.

He had to be assessed by ACAT (Aged Care Assessment Team) because there was no one else to assess him. I just had to hand back 63 days of respite care (Federally funded) because there was no suitable place in Geelong for him to go. We are crying out for Home First hours (State funded) to be topped up so we can have active night duty because he has severe sleep apnoea. But the Federal and State Governments do not have their acts together.

It broke my heart going through the nursing home process with my 21 year old son. We were shown a mixed room – a man in his 90s in one corner, an elderly lady with dementia in another, and my son was to be put in the other corner.

I went home with my son and cried my eyes out and never went back. So we have never had respite yet.

Submission 47, p.2 (Karingal)

4.21 The failure of services to respond to changes in needs was seen as a further problem. The Hunter Brain Injury Service commented that the lack of long-term case management for young people with traumatic and acquired brain injury is a significant issue. There is inadequate ongoing oversight of the changing needs of clients, particularly in relation to reassessment and/or coordination of services, and crisis intervention that can occur in a timely manner. The Service stated that 'our experience indicates that this contributes significantly to the breakdown of support services at a community and family level, as well as increasing the burden of care for (primarily) family'.²²

4.22 The MND Association stated:

The thing with motor neuron disease is its rapid progression, requiring rapidly changing services to meet rapidly changing needs. One of those needs is supported accommodation. At the moment, many people access aged care services for that support and, as we have outlined in our submission, that is inappropriate. We, like Young People in Nursing Homes, are arguing strongly for much more flexible models of funding to

21 *Committee Hansard* 18.3.05, p.45 (Cerebral Palsy League Qld).

22 *Submission* 18, p.4 (Hunter Brain Injury Service); see also *Submission* 188, p.1 (Headstart Community Access Programme).

allow people to purchase support that will assist them to live in their own homes for longer, allow their carers to continue to contribute to their care and support and enable them to live fulfilling lives while still being part of their own community – and not, because of lack of capacity in their own homes, be forced into an aged care setting...²³

4.23 In some cases the complex care needs of the disabled person become so high that it is no longer possible for families to care for them. Evidence from those supporting people with degenerative diseases and brain tumours indicated that care needs can progress to a very high level which requires specialist support. Care needs for different conditions also progress over different periods of time. For example, with Huntington's Disease, the duration of the illness is approximately 20 years although with better care, some patients live for 25 years. Patients spend approximately 10 years in the community and 10 years in residential care.²⁴ For people with motor neurone disease, progression is rapid and requires ever changing services to meet rapidly changing needs.²⁵

4.24 Southern Health commented that services were often directed to work with people who are at the lower end of care rather than for people at the higher end of care.²⁶ While ParaQuad stated:

A lot of our clients are in nursing homes merely because there are not enough services in the home to accommodate them. After people with these types of disabilities have had their disability for more than 20 years they start getting more and more functional, medical and psychosocial problems – this is not necessarily related to their chronological age – and, as the in-home services do not increase and there is no other service for them, they are therefore forced into nursing homes.²⁷

4.25 The Gippsland Carers Association observed that 'family carers are facing an ever increasing pressure to care at all costs, against an ever-dwindling supply of care support services due to demand outstripping supply'.²⁸

4.26 Supported accommodation was often seen as the preferred option for accommodating disabled people in the community. However, in some cases a person's health needs or behaviour may be such that services in supported accommodation are inadequate. Supported accommodation is also not always available and there are long waiting lists for places in most, if not all, facilities.

23 *Committee Hansard* 26.4.05, p.75 (MND Association of Victoria).

24 *Submission* 194, p.2 (Ms R Curran); see also *Submission* 63, p.3 (Australian HD Association NSW).

25 *Committee Hansard* 26.4.05, p.75 (MND Association of Victoria).

26 *Committee Hansard* 26.4.05, p.32 (Southern Health)

27 *Committee Hansard* 26.4.05, p.76 (ParaQuad Vic).

28 *Submission* 62, p.5 (Gippsland Carers Association).

Mark's story – A Huntington's Disease case history

The following is an example of a typical case the HD Social Workers have experienced.

Mark is 36 years old, single and has never worked.

He lived alone in private rental in Sydney but was evicted for inability to look after his flat and erratic rent payment. He is now living with a sibling in a provincial town and is on a Disability Support Pension. He was originally on Newstart.

Sibling brought him to the HDS [Huntington's Disease Service] at Westmead Hospital where he was diagnosed clinically and on MRI.

Mark has dementia and psychotic thinking; he has been seen by a psychiatrist and prescribed an anti-psychotic drug which he will not take. He requires prompting and supervision with washing, dressing, meal preparation, cleaning and money management and his siblings believe he needs residential care.

He was admitted to Lottie Stewart Hospital for respite/assessment but he absconded after two days as Mark does not believe he has HD. He often goes missing for days, travelling by train to Central Railway Station and not coming home until the early hours of the morning or he may go missing for days.

Action

The Mental Health Team initially would not get involved as HD is not a mental illness 'within the meaning of the Act'. They visited once after a call from the HD psychiatrist. ACAT refused to take referral for...low level hostel assessment because of his age (36) but have accepted referral for Boarding House assessment. He is on a waiting list for this but there are no licensed boarding houses close to his siblings.

He is on a waiting list for Co-options to assist his sibling.

He is on a waiting list for a local case manager.

He is on a waiting list for public housing.

His siblings are adamant that he is not capable of living alone. His reverse day/night sleep pattern and habit of roaming for days will mean he will not be able to be contained at home for services to come but [an assessment] cannot be approved unless services have been tried.

Mark was referred to the NSW HD Service after his eviction and he was already well into his illness.

Submission 63, p.6 (Australian Huntington's Disease Association (NSW)).

4.27 The Gippsland Carers Association pointed to the experience in Victoria where, as at 31 December 2003, there were more than 4000 people aged under 65 years on the supported accommodation needs register. Of these, 83 per cent were for people with an intellectual disability. The average length of time that those with an urgent application for shared supported accommodation was approximately 140 weeks. It should be noted that many individuals received a range of support

services to meet their immediate support needs while awaiting entry to supported accommodation.²⁹

4.28 It was reported that the lack of suitable supported accommodation for people with ABI, resulted in young people being accommodated inappropriately in state accommodation, private rental, caravan parks or at home with a carer. In such circumstances, young people often are unable to obtain adequate services, particularly high need services and to ensure that these are maintained at an adequate level. Often the cost of community services puts them out of reach for those in need. In addition, it was stated that the services are often withdrawn due to the cognitive and behavioural issues associated with some clients because of occupational health and safety risks to workers.³⁰

4.29 The issues surrounding the delivery of disability services is discussed in more detail later in this chapter.

Young people living in an aged care facility

4.30 Many witnesses spoke of the extreme difficulty of reaching a decision to move a young person to an aged care facility and of their frustration that there are few other options. They spoke of the social isolation, the lack of rehabilitation services for those with ABI, and the lack of specialist equipment and palliative care for those with degenerative diseases and other disabilities in facilities that are there to care for the frail elderly. There was also concern that once that difficult decision had been made, barriers exist to young people accessing those facilities and, if circumstances change, for young people to move out.

No other options

4.31 Young people are placed in aged care facilities as there is no other option to meeting their particular needs. Young people move from the community when their requirements can no longer be met by community based services or they may move directly from an acute hospital setting following, for example, a traumatic injury. The Victorian Brain Injury Recovery Association stated:

You are fine one day, but something occurs. You could spend a few days in intensive care and within a fortnight find yourself in a nursing home bed because the acute care hospital needs your bed. If you are lucky you might be medically stable by then. I come across a couple of patients a year who, within two to three weeks of their injury, are already in a nursing home bed.³¹

29 *Submission 62*, p.4 (Gippsland Carers Association) citing Victorian Legislative Council, Question on Notice 880, 22.4.04, p.433.

30 *Submission 18*, p.3 (Hunter Brain Injury Service).

31 *Committee Hansard 26.4.05*, p.77 (Victorian Brain Injury Recovery Association).

4.32 The Younger People in Aged Care Alliance (YPACA) also commented that some young people have been placed in aged care facilities when foster placements failed:

Some young people have gone into the care of the state department. When the department has not been able to find an adequate foster family or the foster placement has broken down, a child in care can end up in a nursing home because there is no other option. They can also end up in hospital.³²

4.33 Witnesses also commented that the lack of palliative care resulted in young people being placed in aged care facilities. The Neuro-Oncology Group of NSW stated that there is no long term palliative care:

Our palliative care service is an acute service, as are a lot of palliative care services around the state. That means they will take only people with acute short-term problems and people who look like they will die in the next couple of weeks. If somebody is going to be there for three or four months they will find a nursing home for them if they can.³³

The Group added that families are often asked to sign a nursing home form prior to entering a palliative care unit.

4.34 Other evidence indicated that families had chosen a nursing home to keep the young person close to them. For example, Liverpool BIRU stated that:

I have known families that will accept a less attractive nursing home because the daughter can visit on the way home from school. That, to them, is more important than a really superb unit.³⁴

4.35 Even when accommodation is being sought in an aged care facility, it can be difficult to get an assessment for a place or to find a place.³⁵ The reluctance to undertake aged care assessments for those under 65 years was raised a number of times in evidence. Under the *Aged Care Act 1997* younger people with disabilities will be accepted into residential aged care only 'where there is no alternative'. The Department of Health and Ageing noted supported accommodation for younger people with disabilities 'appears to fall short of demand for these services' and that residential aged care becomes an 'option of last resort on compassionate grounds'.³⁶

4.36 The guidelines for Aged Care Assessment Teams (ACAT) indicate that younger people with disabilities may be assessed and approved as eligible for residential aged care if they need the intensity, type and model of care provided in

32 *Committee Hansard* 18.3.05, p.45 (YPACA).

33 *Committee Hansard* 11.3.05, p.14 (Neuro-Oncology Group of NSW).

34 *Committee Hansard* 11.3.05, p.21 (Liverpool BIRU).

35 *Submissions* 58, p.5 (Palliative Care Victoria); 63, p.2 (Australian HD Association (NSW)); *Committee Hansard* 11.3.05, p.23 (Liverpool BIRU).

36 *Submission* 191, p.36 (DoHA).

such facilities and no other more appropriate services are available. The Committee received evidence that in some areas ACATs are refusing to assess anyone who is under the age of 65. ParaQuad Victoria noted that this 'means these people are at home and at risk because there are not enough services'. The only alternative is to admit them to the acute sector.³⁷

4.37 There was also evidence that ACATs will not assess people until they have trialled other services. In some cases, trialling other services may be difficult or inappropriate. The NSW Huntington's Disease Association has found that people with HD are often not referred to the NSW Huntington Disease Service until they are well into their illness and it is then too late to trial them at home with these other services.³⁸

4.38 After younger people have been assessed for aged care accommodation, they often encounter long waiting lists. Evidence was received which indicated a reluctance or even refusal by some aged care facilities to provide accommodation.³⁹ Palliative Care Victoria stated that a survey of the placement of MND patients in 2001-2003 showed that for those over 65 years the average time waiting for placement in a nursing home was 81 days. For those under 65 years there was an average wait of 190 days. Of those still waiting to be placed, or who had died before placement, the average wait was 568 days.⁴⁰

4.39 The parents of one young person with ABI commented:

Nursing Homes do not readily accept Young People as they find them too difficult to manage and handle. To get Rod into a Nursing Home in itself was a difficult process and to transfer him to a more conveniently located Nursing Home that is of a satisfactory standard is almost impossible. To get him into this current nursing home we had to convince them by offering to take him out on day trips, bathe him and generally be around to take the pressure off them.

We as parents live some distance away which makes it difficult and expensive to visit regularly, which of course we do! John has a 170km return trip and Karen 110km return trip, and Karen actually lives next door to Coledale Hospital which specializes in nursing and rehabilitation care but cannot take Rod as he is already placed. The catch 22 of the nursing home world.⁴¹

4.40 The NSW Huntington's Disease Association also pointed to the refusal of nursing homes to take people with HD because:

37 *Committee Hansard* 26.4.05, p.79 (ParaQuad Victoria).

38 *Submission* 63, p.5 (Australian HD Association (NSW)); see also *Submission* 87, p.4 (Australian HD Association).

39 *Committee Hansard* 11.3.05, p.34 (Carrington Centennial Trust).

40 *Submission* 58, pp.5-6 (Palliative Care Victoria).

41 *Submission* 27, p.3 (Mr R Thompson).

- their difficult behaviour and they are disruptive to older, frail patients;
- their physical symptoms;
- they require extra food, butter, cream, Sustagen, etc;
- they require extra time for feeding;
- they often require special beds or chairs such as the fallout bed which costs approximately \$2000;
- lack of funding for people with HD because the cognitive impairment does not rate high on the Resident Classification Scale; and
- nursing staff are distressed by having to care for such young patients.⁴²

Funding issues are discussed later in this chapter.

Lack of independence

4.41 Many submissions spoke of the lack of independence of young people in aged care facilities.⁴³ Young residents must comply with the rules of the facility where staff levels and routines are aimed at assisting the very frail and to ensure that all requirements are met within a limited time period. HOPES pointed out that tasks which residents may be able to carry out with time and support are performed by staff on a communal basis. HOPES commented that 'in every aspect of life the resident becomes the receiver of care, never a productive member of the community'.⁴⁴

4.42 One parent reported:

Amber also has no choice about aspects of her daily life that the rest of us take for granted. She is given dinner at about 5pm and then put to bed at approximately 6pm when the elderly residents are in bed. This represents a complete loss of the dignity and independence every young Australian has a right to expect. Amber wants to be able to choose what she would like to eat or drink or what time she goes to bed and also what she wants to wear.⁴⁵

4.43 Liverpool BIRU noted that the routines of aged care facilities also disconnects residents from normal routines such as shopping and preparing meals which provide opportunities to exercise and stimulate rehabilitation therapy as well as allowing participation in, and add a purpose to, life.⁴⁶

4.44 Excessive time in bed, typical of the routine for elderly in nursing care, was an often cited frustration for young residents. The space available for personal

42 *Submission* 63, p.5 (Australian HD Association (NSW)).

43 See for example, *Submissions* 51, p.2 (RDNS).

44 *Submission* 190, p.3 (HOPES Inc).

45 *Submission* 9, p.3 (Ms G Foy).

46 *Submission* 110, p.9 (Liverpool BIRU).

belongings is also small: there is no room for mementos, posters or other personal possessions. The young person may have to relocate rooms as the needs of other residents take priority. This means that they must adjust to new surroundings and may have to 'renegotiate' their relationships with new room partners. Residents receive regular intrusions from other residents who may wander into their room, creating difficulties in protecting their few possessions from loss and maintaining privacy.

Melissa's story – Living among the frail elderly

Melissa is now 31 and is still in her SRS. She was one of 43 people aged between 30-39 in 2004 living in an aged residential facility in Victoria. (Dept. Health and Ageing, 2004) Mislead to believe it catered for people like my sister; she resides in a 'nursing home'. After Melissa was placed I was able to get back on my feet and have been trying to get an appropriate placement for her ever since. Melissa sits among the aged. Her 'spark' for life has gone – she has no friends there and no one able to communicate effectively with her. The facility is catered for the aged, she does not go on 'outings', there are no activities. Her personal appearance is neglected due to the number of beds and shortage of staff. A small thing to you or I, but Melissa loves a bath. For the latter reason she cannot have this simple luxury. Being an aged care facility, there are no appropriate disposal units to cater for her Menstrual Cycle. A simple plastic bag in her room is used.

To cater for the amount of 'residents' tea and coffee are pre made in a large jug with the milk already added. A sight you or I would balk at – A daily standard Melissa has had to live with. Melissa is isolated and feels 'abandoned'. She recently surprised me with her understanding by saying "I need to get out – everyone is old – no one talks to me". My heart breaks over and over when I go to see her. I know where she will be – sitting on her own.

The figures say there are 6000 others like Melissa living an undignifying and 'abandoned' life.(ypinh website) I say undignifying because these are young people – young people who deserve to live in surroundings that suit their age. They are entitled to have appropriate care to match their age. The disabled are the vulnerable of our community yet we cannot provide appropriate accommodation to suit their needs. They are left sitting amongst those who are, to be blunt...waiting to die.

Submission 236, pp.3-4 (Ms Amy Seadon)

Lack of social and emotional support

4.45 The Committee heard evidence that many young people in aged care facilities suffer from depression. Young people may be separated from their partners and/or children and social networks. The partner of one young person in a nursing home stated:

He has set times for meals and you have to try and work around that. It costs about \$11 by taxi. As you can imagine, in any partnership the dynamics change. So it is different.⁴⁷

47 *Committee Hansard 28.4.05, p.51 (HOPES).*

4.46 Those with children find it particularly difficult as there are often no facilities to make visits enjoyable for children. Having parents living with large numbers of very elderly frail residents when they are already trying to cope with separation can be very distressing. Many people reported that their children stopped visiting as they found it too upsetting.

4.47 Many submissions commented that depression was exacerbated by living with the very elderly or demented and witnessing the deaths of older people in their homes.⁴⁸ Many facilities do not have single rooms available so young people must share rooms with people who are elderly and sometimes have dementia. Such living conditions lead to depression, loneliness, frustration and boredom. This compounds problems for those young people already experiencing mood swings and behaviour and impulse control difficulties as a result of their illness or disability such as acquired brain injury. The Liverpool BIRU observed:

More commonly, the person with an ABI in a high level residential aged care facility has cognitive and communication problems and is not able to clearly articulate their views. For some, their distress or frustration with their circumstances becomes manifested in challenging behaviours such as screaming, swearing, throwing objects and hitting out. The person becomes labelled 'difficult' and can become feared by other residents, visitors and sometimes the staff.⁴⁹

4.48 The MS Society of NSW commented that this situation leads to depression and 'it is not unusual for people to "give up and lose hope" and as a result deteriorate very rapidly on admission'.⁵⁰

4.49 Young people in aged care facilities want to be able to maintain and develop community interests and activities and to participate in the community and have a social life. However, all too often they become isolated. Friends are discouraged by the sounds and smells of aged care facilities. The wife of one young person commented:

Friends are reluctant to visit an establishment where all the other elderly residents are wandering around in various stages of dementia or all lined up in the sitting room staring into space.⁵¹

4.50 As a result, young people in aged care facilities receive fewer and fewer visitors as time passes and they lose the opportunity to grow socially with their peers. As one witness commented, 'a nursing home has a very different feel and message to a home in the community'.⁵²

48 *Submission 109*, p.3 (Brain Injury Association of Tasmania).

49 *Submission 110*, p.8 (Liverpool BIRU).

50 *Submission 69*, p.3 (MS Society of NSW).

51 *Submission 91*, p.2 (Mrs J McRae).

52 *Submission 17*, p.1; see also *Submission 81*, p.2 (Spinal Cord Injuries Australia).

4.51 Witnesses also commented that young people in residential aged care are further isolated because in many jurisdictions they are excluded from participating in a range of community based recreation programs provided for people with disabilities as they target people living in the community.⁵³ The Victorian Brain Injury Recovery Association stated:

Once you are in your aged care bed, you cannot access any of the state services: you cannot get a case manager unless you were already on a funded scheme when you went in and you cannot get access to any day programs. You cannot get access to any of the resources that are going to allow you to get out.⁵⁴

4.52 Aged care facilities may also lack appropriate transport and the extra staff needed to enable a disabled person to access community programs. However, Liverpool BIRU noted that 'being able to access such programmes could offer an opportunity to socialise with peers and participate in everyday community life'.⁵⁵

4.53 Entertainment and activities within facilities are aimed at the aged. One parent noted that entertainment and stimulus in his son's aged care facility are sing-a-longs of songs from the early 1900s, bingos etc.⁵⁶ This situation is exacerbated as the majority of aged residents are female and the majority of young residents with ABI are male.⁵⁷

4.54 Another submitter commented on a young girl in an aged care facility:

Providing her with the ongoing stimulation and interaction that she so badly needs to feel part of society has proved extremely difficult. The aged care facility is somewhat out of the way, but is the only facility available. Fiona has no interaction that I have observed with other residents, noting that her own behaviours have been reported at times as being challenging (I have not personally observed any particularly challenging behaviours from her). Nevertheless, I believe that many of the behavioural problems she has experienced are a direct result of the inappropriate treatment and isolation she has experienced within an aged care facility. For example, despite repeated requests and Fiona's known wishes, she was repeatedly showered by male staff.⁵⁸

Lack of support for specific needs

We have seen a deterioration in Fiona in the last 12 months. I have to say her level of emotional and psychological trauma over her four years in an aged care facility is more severe than the psychological and emotional

53 See for example, *Submission 125*, p.8 (ACS SA &NT).

54 *Committee Hansard 26.4.05*, p.85 (Victorian Brain Injury Recovery Association).

55 *Submission 110*, p.11 (Liverpool BIRU).

56 *Submission 27*, p.4 (Mr R Thompson).

57 *Submission 110*, p.10 (Liverpool BIRU).

58 *Submission 76*, p.2 (Mr A Witherby).

trauma she has experienced as a consequence of a severe brain injury. That is the quality of the environment we have been dealing with.⁵⁹

4.55 One common problem facing young disabled people in aged care facilities is the lack of time and skills of staff to address their specific needs. For example, the MND Association of NSW noted that people with motor neurone disease may have severe communication difficulties which are often mistaken for intellectual impairment. If staff do not take the time to understand the person, this can be very isolating and frustrating especially for younger people with MND.⁶⁰

4.56 The Victorian Brain Injury Recovery Association provided this example of the difficulties of providing adequate services in some aged care facilities:

...the therapist was coming into the nursing home, but the nursing home staff resented therapists coming in and they resented the physio coming in and showing them how to settle this man so he could be comfortable in bed. They assessed that he had no pain, whereas we were going in and saying: 'This man's stuck up in his bed like this. This man is clearly distressed.' The physio would show them how to have him as relaxed as can be and how he could communicate. The nursing home did not want anything to do with that. They said their nurses knew how to do it and they did not want the therapists there. So his wife has taken this man home.⁶¹

4.57 It was also noted that severe ABI residents may exhibit behavioural problems such as shouting, inhibition, wandering, 'hitting out' arm and leg movements. This is seen as disruptive and unacceptable behaviour. In the case of one person supported by Liverpool BIRU, assistance was offered with designing and implementing a behaviour management plan oversights by staff from the BIRU. The program was not able to be instituted because, even with education, the facility could not provide sufficient and consistent staffing to implement the program. The facility then sought the person's admission to a psychiatric hospital. This was refused as the person's problems stemmed from their brain injury and not mental illness. As a result, 'pressure was inappropriately placed on the family to take the young man home'.⁶²

4.58 The Physical Disability Council of Australia also commented that residential aged care facilities were not obliged to respond to the changing needs of younger people with disability, either via monitoring and reassessment or development of an Individual Service Plan as required of disability services in some States, such as NSW.⁶³ The Neuro-Oncology Group of NSW supported this view and provided the following example of a women who had died of a brain tumour in a nursing home:

59 *Committee Hansard* 11.3.05, p.73 (Mr C Way).

60 *Submission* 42, p.2 (MND Association of NSW). See also *Submission* 58, p.3 (Palliative Care Victoria).

61 *Committee Hansard* 26.4.05, p.87 (Victorian Brain Injury Recovery Association).

62 *Submission* 110, p.14 (Liverpool BIRU).

63 *Submission* 164, p.13 (Physical Disability Council of Australia).

Her swallowing needs, her need for speech pathology, changed in a matter of days. The relative came in to find her mum with a mouthful of food. We do not know how long she had been there like that, because yesterday she could swallow and the next day she could not. That is the sort of fluctuation that can happen with people with brain tumours. They did not have that regular review of equipment needs, swallowing needs, physiotherapy needs. So the allied health element is fantastic and a really important part of things.⁶⁴

4.59 The Darwin Community Legal Aid Service highlighted the problems of young Indigenous people in aged care facilities. It noted that most were from remote Northern Territory communities, placed in the facilities under Adult Guardianship Orders. They had little contact with family members who cannot afford to travel to visit them in urban centres. Their first language is usually an Aboriginal language. The Service stated that young people are disproportionately represented in physically aggressive incidents at facilities with allegations of sexual and physical assault against frail elderly residents.⁶⁵

4.60 The Australian Huntington's Disease Association (NSW) concluded:

Young people with disabilities living in nursing homes do not experience the same rights and standards recognised in the *Disability Services Act 1987*. This is because funding for the frail aged is provided by the Commonwealth Government and the responsibility for the provision of care for young people with disability, including those with Huntington Disease lies with the various State Governments.⁶⁶

Lack of appropriate rehabilitation and other services

4.61 Submissions commented that aged care facilities were often ill equipped to provide appropriate rehabilitation and allied health services including occupational therapy, physical therapy, speech therapy/pathology and high level medical care.⁶⁷

Rehabilitation

4.62 The Committee heard that for people with brain injury, slow improvements can be made over a lengthy period of time either spontaneously or with appropriate rehabilitation. Others may make few gains but have the potential to maintain their abilities. There were many examples given in evidence of the importance of rehabilitation. There were cases where young people who had been aged care facilities

64 *Committee Hansard* 21.3.05, p.21 (Neuro-Oncology Group NSW).

65 *Submission* 60, p.2 (Darwin Community Legal Aid); see also *Submission* 164, p.12 (Physical Disability Council of Australia).

66 *Submission* 63, p.1 (Australian Huntington's Disease Association (NSW)).

67 See for example, *Submissions* 119, p.2 (ABI Behaviour Consultancy); 126, p.3 (Inability Possability Inc); 157, p.1 (Headway Vic); 167, p.3 (ACT Disability, Aged & Carer Advocacy Service);

for some years had, with appropriate rehabilitation, been able to progress to the point where they were able to move into the community. For example, the Victorian program ABI: Slow to Recover provided cases studies of its work which emphasised rehabilitation.

4.63 While programs like ABI: Slow to Recover may be delivered in aged care facilities, it is the exception rather than the norm. The Liverpool BIRU noted that when older people moved to an aged care facility, provision of care increases as their health deteriorates and abilities are lost. It stated 'that continuum from a rehabilitation-enabling focus to helping someone to move on with their life is lost when people go to nursing homes, because they are different structures'.⁶⁸ Liverpool BIRU concluded that 'this means that we have young people attempting to continue their rehabilitation and live a life with meaning in a milieu that is oriented to assisting older people maintain their abilities, manage their deteriorating health and end their life with dignity'.⁶⁹

4.64 The Liverpool BIRU went on to note that it is very difficult to provide individual rehabilitation in aged care facilities. For example, people with memory problems may need visual prompts to help them remember to undertake certain tasks: leaving a person's toothbrush and toothpaste near the hand basin may prompt them to remember to clean their teeth. Rehabilitation is also time consuming and there are limited opportunities for one-on-one rehabilitation activities in high level aged care facilities. NAYPINH commented that therapy services paid for out of bed subsidies are severely rationed across all residents and 'are nowhere near enough to meet the needs of a younger person'.⁷⁰ One submitter observed:

The Facility has neither the time, resources or staff to undertake rehabilitation. They do not see that they are funded to do so, either. In fact from their own management perspective, I suspect [the young person] is much easier to deal with, being currently unable to walk, then she would be with further rehabilitation although I believe she has the physical capacity to recover many critical skills, such as walking.⁷¹

4.65 The impact of the lack of rehabilitation on individuals can be significant. Headway Victoria provided this case study:

A young man entered a nursing home following a traumatic brain injury. At the point of entering the facility he was able to manage his own transfers from bed to wheelchair and wheelchair to toilet with assistance. However, staff found this to be too intensive and were concerned about back injuries. They insisted on the use of a hoist even though the man was in an active rehabilitation mode and being able to do his own transfers was a

68 *Committee Hansard* 11.3.05, p.16 (Liverpool BIRU).

69 *Submission* 110, p.7 (Liverpool BIRU); see also *Submission* 205 (VBIRA).

70 *Submission* 160 p.9 (NAYPINH).

71 *Submission* 76, p.3 (Mr A Witherby).

requirement of him being able to move out of the facility. Over time, through lack of regular reinforcement, his ability to manage his transfers declined.

The lack of priority given to the rehabilitation goals of the individual is the key issue here. Nursing staff can often consider therapeutic input as the role of therapists however the rehabilitation potential of the individual is best supported by a coordinated approach across the disciplines.⁷²

4.66 The importance of rehabilitation is not limited to those with acquired brain injury. Those suffering from degenerative diseases also require therapy.

4.67 Witnesses commented that younger people residing in nursing homes are precluded from funding that could provide further rehabilitation or access to community social and recreational programs and other disability services. It was viewed that once a person moved into aged care accommodation, funding for these services were not provided by State authorities.⁷³ Many witnesses commented that once a person moves from a community based support package to Commonwealth aged residential facilities, they cannot access disability services under Commonwealth State and Territory Disability Agreement (CSTDA) even though they are part of the CSTDA target group.⁷⁴ The Agreement is discussed further in this chapter.

Provision of specialised equipment

4.68 The Committee also heard of the lack of appropriate equipment required by some residents. In evidence it was stated that in some jurisdictions, for example Victoria and NSW, specialised equipment is not available through State programs. As a consequence, electric wheelchairs to facilitate access to the community, electric riser chairs to facilitate comfortable seating for communal activities, appropriate pressure care devices electric adjustable beds and other equipment is not provided.⁷⁵ The MND Association of Victoria noted that residential aged care facilities are required to make available a range of disability equipment but generally only provide minimum equipment or equipment at a basic standard. The Association stated:

Can I say that it is very embarrassing, when we have a person living at home with an electric high-rise bed that bends in the middle and vibrates, that they cannot take that with them when they go into a nursing home, because the electric bed has been provided by the state – and, of course, the Commonwealth does not fund equipment to that level. They also cannot

72 *Submission* 157, p.3 (Headway Vic).

73 *Submissions* 67, p.2 (Barwon South West Acquired Brain Injury Network); 160, p.9 (NAYPINH).

74 See for example, *Committee Hansard* 18.3.05, p.2 (Office of Public Advocate Qld); 28.4.05, p.61 (MS Society of Tasmania); *Submission* 126, p.3 (Inability Possability Inc); *Submission* 160, p.10 (NAYPINH).

75 *Submissions* 110, p.11 (Brain Injury Rehabilitation Unit, Liverpool Health Service); 121, p.5 (Office of the Public Advocate, Victoria); 190, p.2 (HOPES Inc);

take their electric recliner chair, which improves their comfort during the day. They have difficulty accessing appropriate levels of posture support, particularly mattresses to prevent pressure. They are often left in situations where their inability to communicate means that harried and hurried staff do not deliver the services that they need. Quite often, it is only because of interventions from outside the aged care service that their needs are actually met.⁷⁶

4.69 The Committee also heard evidence that some providers did not encourage residents to use specialised equipment. HOPES Inc for example, stated that facilities may discourage younger residents from purchasing their own equipment such as electric wheelchairs in case they run into elderly residents or damage doorways. Should younger residents choose to purchase their own specialised equipment they are responsible for all costs involved. HOPES indicated that this situation leads to increased dependence and reduced physical ability for the younger resident.⁷⁷

4.70 NSW Health responded to the evidence of lack of equipment in aged care facilities. It stated under its Program of Appliance for Disabled People (PADP) people in the community were entitled to equipment. People in nursing homes are entitled to PADP if it is for a piece of customised equipment but, if it is a piece of equipment that can be used by other residents in the residential aged care facility, then NSW stated that is the responsibility of the residential aged care facility to provide. That is within the funding arrangements. Further:

There is a degree of overlap and confusion about that policy. I understand that. We are trying to resolve it. It has been a longstanding issue between the Commonwealth and the state. But PADP is one of the programs that is absolutely critical to supporting people with disability in the community. I know that New South Wales Health has increased its investment in dollar terms by 70 per cent over the last five years, and it is still not enough to be fair.⁷⁸

4.71 ACROD argued that the schemes providing equipment for the disabled are fragmented and that all levels of government should develop a coordinated approach to the provision of aids and appliances and gave the example of the Continence Aids Assistance Scheme where funding is provided by the Commonwealth for those under 65 and those over 65 who work for eight or more hours per week. Those over 65 years and not working must access a State funded scheme.⁷⁹

76 *Committee Hansard* 26.4.05, p.76 (MND Association of Victoria).

77 *Submission* 190, p.2 (HOPES Inc).

78 *Committee Hansard* 19.8.04, pp.54-55 (NSW Health).

79 *Committee Hansard* 11.2.05, p.56 (Australian Council for Rehabilitation of Disabled).

Mary's story- no medical devices from government's cost shifting

Mary is aged 54 and is a resident in a residential aged care facility.

Mary requires a pressure management device on her bed to prevent the occurrence of bed sores, to address chronic hypersensitivity and discomfort, to optimise comfort levels, and to enhance quality of life.

The residential facility is required to provide pressure management devices, and supplies a "ripple foam mattress" which is inappropriate for people with MND, and who require a variable air pressure ripple mattress. The air pressure mattress provides alternating and variable pressure support which optimises comfort, reduces pressure areas and which significantly reduces the requirement for turning of the person and repositioning

The residential aged care facility will not purchase the appropriate pressure care device and the state [Victoria] Aids and Equipment program will not fund people living in residential aged care which is funded by the Commonwealth

Submission 77, p.5 MND Association of Victoria

Risks of living in aged care facilities

4.72 Witnesses also argued that there were risks of mixing severely disabled people with people with dementia. For example, the MND Association of Victoria stated that people with MND living in residential aged care facilities increasingly face the risk of assault or disruption to life support equipment by other residents. Some people with MND require ventilatory support, while many have PEG feeding tubes. This, combined with severe physical disability, can place them at risk of assault or interference with their medical equipment by people who are physically able but suffering from dementia. The Association stated that in one reported instance, a person with dementia had to be restrained from disconnecting ventilation equipment from a person with MND who was unable to protect or defend themselves due to their disability. Other reports had been received of people with dementia abusing and attacking people with MND in their beds. The Association concluded that 'these events highlight the existing risks of having people with severe physical disability but mentally able living in an environment where other residents are physically able but suffering from dementia'.⁸⁰

Impact on staff

4.73 The Australian Nursing Federation commented that it was important to recognise that aged care nursing is a specialised area of nursing. Younger people with disabilities have quite different needs:

80 Submission 77, p.6 (MND Association of Victoria).

Because nursing of older people is a specialised area, nurses who work in aged care – particularly in residential facilities but across the whole community and other settings too – will have those specialised skills for looking after older people. Therefore, it is putting an extra demand on them to also have specialised knowledge of younger people with disabilities which could require quite different care from looking after older people.⁸¹

4.74 Evidence was received that staff suffered as they battled 'with delivering quality care to both groups within a budget designed (for better or worse) for one group'.⁸² The following examples of problems for aged care staff providing care for young people were provided to the Committee:

- There is a lack of appropriate training in working with people with high support needs especially those with Motor Neurone Disease, multiple sclerosis or other similar conditions. ABI Behaviour Consultancy noted that often aged care facilities cannot afford comprehensive training for staff, which typically exceed \$1000 per day for inservice workshops and backfill costs.⁸³
- Nursing young people is physically demanding on staff if the person is in a wheelchair and is unable to weight bare. There are often no lifting machines and the staff have to lift the person manually.
- Staff are not trained in counselling clients and often worry when confronted with a younger client who is depressed and just looking for someone to listen to them.⁸⁴
- Nursing home staff lack the capacity to invest time in communications issues with those who either have lost their capacity to communicate in the usual manner or who never had that capacity.⁸⁵
- The high turnover of staff and use of temporary or agency staff often means that staff on duty are not aware of the specific needs of some people in the facility. The MND Association of Victoria gave the example of a person with MND, with no use of their arms or ability to speak, being delivered meals, but because they cannot feed themselves. The meals are taken away uneaten, and the person is unable to communicate that they need to be fed. The information regarding feeding and communication is available in the patient file.⁸⁶
- Many facilities face chronic staff shortages and there is little or no time to provide the necessary attention for high needs patients, for example, people

81 *Committee Hansard* 11.2.05, p.39 (ANF).

82 *Submission* 8, p.3 (Horton House).

83 *Submissions* 119, p.2 (ABI Behaviour Consultancy).

84 *Submission* 10, p.1 (Ms V Smith).

85 *Submission* 58, p.3 (Palliative Care Vic).

86 *Submission* 77, p.5 (MND Association of Victoria).

with MND require PEG feeding and/or ventilation.⁸⁷ In addition staff are not trained to deal with people who exhibit behavioural problems:

As a result of his brain injury, Rod exhibits antisocial and abnormal behaviour. Nursing Home Staff are usually intimidated by his behaviour and either spend minimal time with him or avoid him all together. Staff have complained to Management about his behaviour. (What more evidence could one need of a complete lack of training for such patients.) They do not know how to deal with him so they choose to ignore him as much as possible. There is little or no empathy.⁸⁸

4.75 The ANF Victorian Branch noted that there is currently no ability for homes with residents with severe behavioural problems to access funding for additional resources to manage such clients, either in the short or long term. In the past, this has led to some facilities attempting to evict a resident in order to protect other residents and staff or trying to get such people back into a public hospital.⁸⁹

Moving young people out of aged care facilities

...we need to move beyond the scoping, the data gathering, the researching and the counting to actually piloting some of these initiatives across the country to a greater extent than has been done already, as well as putting in place measures to prevent more younger people from entering nursing homes.⁹⁰

I have gone on reference groups, I have watched studies being done and, at the bottom line, we are still in the same position as we were at St Vincent's eight years ago. There is no where for Chris to go.⁹¹

4.76 Witnesses called on government to institute programs to move young people out of inappropriate aged care facilities. NAYPINH recommended the establishment of a National Exit Program with a target of moving 700 young people per year out of aged care facilities. NAYPINH estimated that it would cost on average \$49 million per year to achieve this target. NAYPINH argued that a range of accommodation options and support options for young people in aged care facilities is achievable, necessary and cost effective.⁹² It noted that there were examples where young people had been successfully moved out of aged care facilities. In Western Australia, for example, 95 young people resident in aged care facilities had been moved back into the community over a period of approximately four years.⁹³

87 *Submission 42*, p.2 (MND Association of NSW); 58, p.3 (Palliative Care Vic).

88 *Submission 27*, p.3 (Mr R Thompson).

89 *Submission 66*, p.3 (ANF Victorian Branch).

90 *Committee Hansard 18.3.05*, p.2 (Office of Public Advocate Qld).

91 *Committee Hansard 26.4.05*, p.90 (Mrs M Nolan).

92 *Submission 160*, p.26 (NAPYINH).

93 *Submission 160*, Supplementary Submission, p.6 (NAYPINH).

4.77 YPACA argued that the Commonwealth needs to take a leadership role by linking outcomes, that is the number of people no longer in aged care facilities who are leading quality lives in accommodation of choice, to state funding levels. This would ensure that funds were quarantined for this purpose.⁹⁴

Models of accommodation services

Most people want to stay at home, but not everybody. The best care is flexible care that allows people to have some options. You cannot get one package that fits everybody.⁹⁵

The critical factor should not be the age of the person but rather the need for high level nursing care.⁹⁶

4.78 As part of its inquiry, the Committee visited four facilities providing care for younger people with disabilities. In Victoria, Carnegie House provides accommodation for three people with MS; in Western Australia the Committee saw models of care that were Huntington's Disease specific, MS specific and brain injury specific. In evidence, the Committee received a range of views on they type of accommodation required for young people in residential aged care facilities and those at risk of moving into aged care. Some groups supported the development of innovative models of cluster or congregate housing, some conceded that certain individuals may require a more intensive medical care setting while others argued that all care should be provided individually in the community.

4.79 The concept of cluster or congregate housing drew a range of comments from witnesses. Some concerns were raised about institutionalisation, lack of privacy and choice and past poor experience. YPACA stated that it did not support cluster accommodation, 'where eight people are congregated together because they may have similar needs and because there is a building there for it'.⁹⁷

4.80 YPACA also commented that special purpose nursing homes, cluster homes and other forms of enforced congregation were not a solution.⁹⁸ They represented a form of institution and are a service provision that is imposed on people with disabilities. YPACA proposed a person-centred approach and pointed to examples of people with quite significant needs associated with their disability who live in the community in their own homes:

There are many models out there of people with very high support needs living in the community. We are proposing to start from where the person is and what supports the person needs, not from an eight-bed facility or

94 *Submission 56*, p.1 (YPACA).

95 *Committee Hansard 11.3.05*, p.18 (Neuro-Oncology Group of NSW).

96 *Submission 194*, p.2 (Ms R Curran).

97 *Committee Hansard 18.3.05*, pp.35-36 (YPACA)

98 *Submission 56*, p.1 (YPACA).

whatever...the health needs can be met through domiciliary nursing services that come in through regular health systems et cetera. Personal carers are very well trained⁹⁹

4.81 The Cerebral Palsy League of Queensland is proposing to utilise a model which involves a number of houses within a suburb where two or three people may live. Carers are able to provide services to people who live nearby but there is not a 'cluster' and residents can be part of the community.¹⁰⁰

4.82 NCOSS stated that congregate care was not supported in New South Wales. Instead, 'the disability sector in New South Wales will be pushing very much for as small as possible and as integrated as possible'. NCOSS saw some dangers in congregate care:

There are some dangers in creating congregate care that restricts opportunity and restricts involvement. It can also restrict involvement of the family, and we would need that to be monitored. In New South Wales there has been a problem with disability services in that they have not received any deliberate or structural monitoring for over four years. We are very concerned that should processes be set up without that monitoring and quality at the front end services would again be relaxed and we would get into institutionalisation.¹⁰¹

4.83 The Office of the Public Advocate Queensland also argued that, for some, congregate care raises concerns. There are examples where congregate care has led to segregation of people and where the values that are brought to bear by the people who are working there are less than optimal. The Office of Public Advocate stated:

What I am aware of without any doubt is that in Queensland we have quite a few mini-institutions which look like ordinary suburban houses. They are mini-institutions because of the institutional mindset brought to them by some of the people that work in them. Some of the other group homes are completely different from those. I have been to group homes that look and feel like homes. It varies greatly, depending upon the ingredients and the mix.¹⁰²

4.84 The Office of the Public Advocate went on to comment that congregate care models probably work where people will clearly benefit from being together and choose to do so. If people do not have a say in where they live and with whom they live, difficulties may arise: where congregate arrangements are 'meaningful and related to the individual needs and aspirations of the people they can work'.¹⁰³

99 *Committee Hansard* 18.3.05, p.34 (YPACA)

100 *Committee Hansard* 18.3.05, p.36 (Cerebral Palsy League Qld).

101 *Committee Hansard* 11.3.05, p.54 (NCOSS).

102 *Committee Hansard* 18.3.05, p.8 (Office of Public Advocate, Qld).

103 *Committee Hansard* 18.3.05, p.8 (Office of Public Advocate, Qld).

4.85 NAYPINH reported that in Victoria, 'the Government's ideological stance will not countenance the development of shared supported accommodation settings because "congregate" care is seen to be outdated and irrelevant'. However, they stated:

It remains a fact that the states have stopped developing congregate living situations. The fact that social interaction and community are vital for young people fails to impact this entrenched and fashionable view, a detail which demonstrates that if responses are left to the dictates of policy alone, they will inevitably fail.¹⁰⁴

4.86 Witnesses also provided evidence of where an individual package had been developed to meet particular needs. In Hervey Bay in Queensland, former residents of the Bush Children's Service are now supported by a community based service which is administered by a registered nurse. The Office of the Public Advocate commented:

The notion of an almost mobile medical service seems to be a critical part of arrangements that work well for this cohort...These are very individualised arrangements. Two or three people might live together but it certainly has an individual focus...We are talking about very fragile people who get that level of support within their own home in the community.¹⁰⁵

4.87 The MND Association of Victoria also supported individual programs aimed at keeping people in their own homes and stated 'the minute you start talking about facilities you immediately stop thinking...If you are going to bury money and infrastructure in a building, for example, it is locked up for ever. The minute you get three people in there with long-term disabilities that facility is effectively taken out of the available options for other people'. The MND Association supported keeping people in their homes:

One of the best ways to keep people at home is to invest in case coordination and case management that can help look at the services that are available within a community. Self-care packages can be developed with friends, relatives and neighbours within the local community to help that person remain at home for longer...That means there are no facility costs. They are with their carer. With small amounts of brokerage, we can bring in enough services to help them remain at home and to help the carer keep on caring better for longer.¹⁰⁶

4.88 While aged care accommodation was generally not supported, there was evidence that this may remain a viable choice for some people. The Committee was provided with examples where there were benefits from proximity to family and networks.¹⁰⁷ In some cases, the complex needs of a person may only be met in a nursing home setting and it was mooted that groups of people could be accommodated

104 *Submission* 160, p.7 (NAYPINH).

105 *Committee Hansard* 18.3.05, p.9 (Office of Public Advocate, Qld).

106 *Committee Hansard* 26.4.05, p.80 (MND Association of Victoria).

107 *Committee Hansard* 18.3.05, p.9 (Office of Public Advocate, Qld).

in a cluster or specially set aside area or wing in an aged care facility. The Queensland Government commented that individual circumstances and issues needed to be examined in order to assess the appropriateness of aged care accommodation.

It is important to acknowledge accommodation of some younger people with a disability in such facilities may not be inappropriate and may be the most practicable option. It is desirable to provide age appropriate care and age appropriate facilities/circumstances...

Younger people with a disability due to degenerative diseases such as muscular dystrophy, multiple sclerosis or motor neurone disease may enter an aged care facility towards the end stage of life when high levels of care may be required.

It is also evident that some people with a disability access aged care facilities due to an early onset ageing condition. In these instances the need for aged care nursing may outweigh the need for disability support. For example, people with certain disabilities such as Downs Syndrome are more prone to early onset dementia conditions. As these ageing conditions progress, the individual may reach a point where their need for aged care and monitoring outweighs their need for disability support.¹⁰⁸

4.89 The AMA pointed to the particular difficulties of providing facilities for young people in rural and regional areas. As there may not be enough young people with disabilities to justify a stand alone facility in each town, the AMA commented that it may be necessary to redefine the roles of some residential facilities. This would enable them to improve the scope of the services that they provide to better meet the needs of all residents. The AMA concluded:

In this way, a new type of residential home would emerge in regional and rural areas, providing services for people of all ages with complex, chronic conditions and disabilities, with staff trained in and sensitive to the needs of younger people with disabilities.¹⁰⁹

4.90 NAYPINH also commented on the provision of services in rural areas:

Young people in remote or rural areas may choose, because the numbers are not as high or the services do not exist, to remain in a nursing home because it keeps them near their family and friends. If that were the case, then the states would be responsible for providing the funding to take the services into the nursing home that these young people do not currently get – services around equipment, physio, rehab, higher staffing ratios and so on.¹¹⁰

4.91 Liverpool BIRU supported some accommodation in aged care facilities but as a cluster attached to the facility:

108 *Submission* 193, p.12 (Queensland Government).

109 *Submission* 129, p.7 (AMA).

110 *Committee Hansard* 26.4.05, p.65 (NAYPINH).

Some people will be managed really well in a nursing home because it has the infrastructure that is required by that person and the location is close to their family. If there were clusters then there would be expertise, and that would resolve some of the issues that we found in looking at the problems of people living in nursing homes.

This arrangement was described as resourcing a small group in a different way than the rest of residential population.¹¹¹

4.92 The Australian Huntington's Disease Association of NSW commented that accommodation solutions come back to the actual disability:

Because of the progressive nature of Huntington's Disease there are going to be people under the age of 65 who require a nursing home standard of care. But they need those extra bits, such as being perhaps in a cluster or group. Similar to the way you might have a dementia specific unit in a nursing home, you might have a Huntington's specific unit which young people would be in together. They would not be sharing rooms. They would get extra things, such as being taken out, as well as the extra food they need, the extra time they need for feeding and all those sorts of things.¹¹²

4.93 The MS Society of Victoria provided the example of Cyril Jewell House at Keilor. This is a facility for 15 people attached by a passageway to a 30-bed nursing home. Core funding is provided by the Department of Health and Ageing and top up disability funding from the Victorian Department of Human Services. The Society commented that this funding works well in providing additional care resources and a community access service that assists residents to get out into the community.¹¹³

4.94 Carnegie House in Victoria and Fern River in Western Australia provide examples of shared supported accommodation. Carnegie is a three bed house for people with MS. It is funded by both the Commonwealth and the State:

...for the Carnegie house and also for a second innovative pool pilot we have at a shared supported accommodation service that we also run, the Commonwealth funding is used for nursing and therapy and the state funding is used to provide personal-care attendance and community access. It is almost broken up down the lines of clinical services and non-clinical services – personal-care attendants and trained staff. The Victorian government, as well as other governments, has a significant problem with accepting that nursing services are an essential part of a disability service.¹¹⁴

111 *Committee Hansard* 11.3.05, pp.16,19 (Liverpool BIRU).

112 *Committee Hansard* 19.8.04, p.8 (Australian HD Association of NSW).

113 *Submission* 175, p.3 (MS Society of Vic).

114 *Committee Hansard* 26.4.05, p.64 (MS Society Australia).

4.95 Fern River provides six supported units with three people in each unit. There are 24-hour on-site carers. Funding is provided by both the Commonwealth and the State as the Young People in Nursing Homes Project.¹¹⁵

Amber's story – Changes to lifestyle after moving out of a nursing home

Amber is 30 years old and has Cerebral Palsy and an intellectual disability. After six years of living in a nursing home she has moved into supported accommodation. After six days in the supported accommodation, her mother wrote:

Amber has settled into the home extremely well and already there is a difference in her personality. She is laughing, which is something she has not done for a long time. She is also interacting with the other clients very well and the carers at the home are surprised with how well she has adjusted to the move in such a short period of time.

Amber now has a choice of what she would like to do, what time she wants to get to bed and what she wants to eat and even what clothes she would like to wear for the day. She had none of these choices at the nursing home. She Doesn't have to go to bed at 5.30 pm anymore and her food is home cooked, not pureed hospital food.

Amber can now access physiotherapists, occupational therapists and speech therapists. She was never able to do this in the nursing home. Amber lost her ability to use sign language, to chew her food properly, as it was pureed; she also lost a lot of muscle tone because of the lack of exercise and her weight dropped down to 39 kilos.

She does not have to endure the indignity of having to take laxatives and given suppositories for her bowels anymore. With nutritional food and exercise her bowels should work normally again.

Amber's personality is really shining through since she has left the nursing home. At long last she has a life worth living.

Submission 217, p.2 (Ms G Foyle).

An individual approach

4.96 Witnesses were wary of supporting the development of one proposal or one model of accommodation because of the nature and the range of disabilities.¹¹⁶ It was acknowledged that there is a finite range of service models available but it was argued that the States and the Commonwealth should develop a range of options for support and accommodation.¹¹⁷

4.97 While there was debate about the type of accommodation model, there was general support for an individualised approach, namely that the needs and wants of the

115 *Committee Hansard* 23.2.05, p.38 (MS Society Western Australia).

116 *Committee Hansard* 11.3.05, p.53 (NCOSS).

117 *Committee Hansard* 18.3.05, p.2 (Office of Public Advocate, Qld).

individual should be paramount. The MND Association of Victoria, for example, stated:

Where younger people with disabilities and people living with MND require "nursing home" levels of support, services should be made available in an environment that delivers services based on the needs created by their disability, not their age, and not services based on an age group needs other than theirs. Services must be focussed on addressing the needs created by the disability, not on the delivery of a generic service model. Services need to be individualised and focussed, with packages of support being used to optimise outcomes.¹¹⁸

4.98 The MS Society of Victoria provided details of individual care plans which move away from systems and pre-determined programs and concentrate planning around an individual and his or her needs.¹¹⁹

4.99 The Office of the Public Advocate Qld commented while there are pockets of good practice these need to be extended across the country:

The impression I get – and we have not surveyed nationally to any degree – is that there is a generalised situation of people under the age of 65 in nursing homes and then there are spots of good practice. Beverley has identified the one in Hervey Bay. We are aware of Western Australia with a cohort with multiple sclerosis that were moved out. You will probably find in each jurisdiction that, hopefully, there would be some good practice, but it has not been addressed systemically to bring that good practice to bear on a fairly major cohort of people.¹²⁰

4.100 In order for an individualised approach to be successful, a number of options need to be available. NAYPINH supported extending the range of options to enable young people and their families to have a choice about where they live and how they are supported. NAYPINH noted that for the 95 young people moved back into the community in Western Australia, 20 new supported accommodation options developed. These included moving home with supports to live with family, moving into dedicated facilities designed to support individuals with Huntington's Disease, group homes and moving to nursing homes in country towns to be closer to family and friends.¹²¹ The Alliance concluded:

Whatever supported accommodation 'option on the spectrum' a young person chooses, it needs to function as a real home: a home to leave from and a home to return to.¹²²

118 *Submission 77*, p.7 (MND Association of Victoria).

119 *Submission 175*, p.5 (MS Society of Victoria).

120 *Committee Hansard 18.3.05*, p.10 (Office of Public Advocate, Qld).

121 *Submission 160*, Supplementary Submission, p.6 (NAYPINH).

122 *Submission 160*, Supplementary Submission, p.12 (NAYPINH).

4.101 Witnesses argued that the main barriers to ensuring that a range of options and model services were available include funding difficulties; fragmentation of services both across and within jurisdictions; and lack of leadership. NAYPINH commented the Western Australian project succeeded because:

it had an excellent process in place from the outset; and the money, energy and desire to achieve the changes it wanted. It shows that with the political will and desire to do something and a dedicated funding stream to do it, success is possible.¹²³

Current funding arrangements

It appears that because Todd has been classified as being eligible for nursing home placement, he is doomed to spend the rest of his life there. I believe that State and Federal government policies are part of this problem. Why would the state funded DADHC want to take on the costs of Todd's care, when he is being 'looked after' by the federally funded nursing home. Because you are in one, excludes you from the other.¹²⁴

Aged Care Act

4.102 As noted above, young people may be accommodated in aged care facilities if there is no other option. For Commonwealth funded accommodation, an Aged Care Assessment Team (ACAT) assesses the person's needs and they receive a Resident Classification Scale (RCS) level. The majority of younger residents receive RCS level 1-3 subsidies (high care levels). Those young people in nursing homes who receive the disability support pension are classed as concessional residents, entitling the provider to the concessional resident supplement.¹²⁵ The basic subsidy amount is supplemented by other payments including oxygen supplement and enteral feeding supplement.¹²⁶

4.103 Many witnesses pointed out that the ACAT's assessment is designed to measure the multiple pathologies of elderly people, which were described as 'lots of little problems associated with ageing, where you can claim in every question as part of the RCS'.¹²⁷ However, many younger people in aged care facilities have complex medical needs, for example, ventilator support and gastrostomy meals and also require a high level of physical assistance. It was argued that the RCS does not capture the care needs of younger people who have major deficits in particular areas, nor does it take into account the person's psychosocial needs which mostly stem from the

123 *Submission* 160, Supplementary Submission, p.7 (NAYPINH).

124 *Submission* 91, p.4 (Mrs J McRae).

125 Hogan WP, *Review of Pricing Arrangements in Residential Aged Care, Final Report*, Canberra, 2004, p.254.

126 Hogan Review, p.202.

127 *Committee Hansard* 11.3.05, p.25 (Carrington Centennial Trust).

particular age group they are in.¹²⁸ The Physical Disability Council of Australia also commented that the ACAT's assessment may underestimate or discount cognitive, behavioural, support, cultural and personal issues.¹²⁹ In addition, ACROD stated 'funding formulae have failed to keep pace with the real costs of assisting people who have complex medical support needs'.¹³⁰

4.104 NSW Health commented that the RCS assumes a model whereby funding levels decrease as independence increases. In the case of a younger person who has an acquired brain injury, for example, therapy needs may intensify as rehabilitation progresses, resulting in the need for greater funding levels, or at least maintenance of funding to meet therapy costs.¹³¹

Residential aged care subsidies

4.105 Many witnesses argued that residential aged care subsidies were insufficient to meet the needs of those younger people with high needs in aged care facilities.¹³² For example, the Carrington Centennial Trust, an aged care facility which provides care for a number of young people, submitted that younger persons require higher numbers of staff hours to meet their nursing and exercise needs than aged residents. In a case provided by the Trust, a young person required a total 8.9 hours of care per day, excluding diversional therapy, compared with 5.1 hours of nursing care provided to a Category 1 frail aged resident. The young person with ABI was assessed as a Resident Classification Scale Category 2 attracting funding of \$94.76 per day. The frail elderly resident was assessed as Category 1 and received \$105.57 per day. The Trust noted that 'despite the younger person requiring more intensive type of care and therapies, the RCS fails to recognise this state of affairs'.¹³³

4.106 The CEO of the Trust stated that it had been approached to take other young people but stated that it could not 'fund \$98 000 or \$100 000...to care for a younger disabled person, when I can get someone who is 75 or 78 coming into a nursing home and the level of funding is commensurate with the level of care I am giving'.¹³⁴

4.107 In comparing the funding levels in residential aged care facilities and disability services, it was noted that the maximum subsidy received in residential aged

128 *Submission* 126, p.3 (Inability Possability Inc).

129 *Submission* 164, p.13 (Physical Disability Council of Australia).

130 *Submission* 26, p.4 (ACROD).

131 *Submission* 202, p.12 (NSW Health).

132 See for example, *Submission* 8, p.3 (Horton House); *Submission* 200, p.6 (Tasmanian Government).

133 *Submission* 85, p.6 (Carrington Centennial Trust).

134 *Committee Hansard* 11.3.05 (Carrington Centennial Trust).

care is around \$43 000.¹³⁵ NAYPINH stated that funding levels for young people in the community may range from \$75 000 to \$90 000 per annum in the non-government sector and that in some States the cost per head for a disability service may be as much as \$107 000.¹³⁶ NAYPINH provided this more detailed analysis of comparative funding:

Table 4.2: Comparative funding for a young person through disability services and for a young person in residential aged care

Indicative person with a disability with full service		YPINH with high needs	
CRU Accommodation	\$57 000	Category 1 bed fee	\$43 000
Day Activity program	\$22 000	Supplements	\$1 000
Transport (mobility allowance)	\$1 500	Day Activity	unmet
Case Management	\$2 500	Equipment	unmet
Transport	own cost	Therapy	unmet
Total	\$82 500		\$44 000

Source: Submission 160, p.23 (NAYPINH)

4.108 The MS Society Australia commented:

We see perverse situations where someone will be sitting in a state disability bed worth somewhere between \$60,000 and \$80,000 a year and then, because they need a higher level of support, they get moved on to a service that is worth \$45,000 a year just because there is a registered nurse on the premises.¹³⁷

4.109 The NAYPINH concluded that:

While it is difficult to draw exact comparisons across funding jurisdictions and individuals, it is clear that the aged care subsidy model with its various care levels is not designed for younger people with disabilities...The current subsidy arrangements cannot meet their needs without substantial cost subsidisation of care resources from other residents in the same facility.¹³⁸

135 *Committee Hansard* 18.3.05, p.2 (Office of Public Advocate Qld); *Submission* 160, p.22 (NAYPINH).

136 *Submission* 160, p.22 (NAYPINH).

137 *Committee Hansard* 26.4.05, p.67 (MS Society Australia).

138 *Submission* 160, p.23 (NAYPINH).

4.110 The NAYPINH went on to argue that it was the Commonwealth's responsibility to provide adequate care for young people in aged care facilities even those that are there 'due to the failure of the CSTDA jurisdictions and other systems...failure to give due recognition to genuine need will not suppress its existence'. The NAYPINH believed that younger people will continue to reside in residential aged care facilities because of 'demand issues in State Disability Services, pressure on acute care beds, geographical considerations and the sheer force of timing demands between the competing interests of health and disability'. As such, it argued that the Commonwealth should provide increased services levels and targeted standards through the Aged Care Act for young people in nursing homes.¹³⁹

4.111 This argument was echoed by VBIRA which stated that:

VBIRA realises that persons with severe ABI have been admitted to government supported nursing homes for many years, not because they fit the requirements of being frail and aged but under emergency or compassion provisions of the federal and state agreements, where the state has no other option available. By persisting with this practice CSTDA after CSTDA...the federal government has by default accepted responsibility for funding the accommodation and care of persons who need special care and rehabilitation. Actions speak louder than words.¹⁴⁰

Innovative Pool

4.112 Under the Aged Care Innovative Pool, the Commonwealth has offered flexible aged care places to the States and Territories and other aged care providers for time limited pilots for the provision of aged care services in new ways and for new models of partnership and collaboration. In 2002-03 two specific categories of people with a disability were targeted. The first were people with disabilities who are ageing and the second were younger people with disabilities in residential aged care who would be more appropriately placed in disability-funded accommodation.

4.113 DoHA stated that while nine projects were approved in 2002-04 for people ageing with a disability, no applications were received in 2002-03 for projects for younger people in nursing homes. In 2003-04, one pilot project was approved for the MS Society of Victoria to assist the transition of younger people with disabilities from aged care homes to more appropriate accommodation. Carnegie House provides three places funded by the Commonwealth over two years. No other States have taken up funding under the Innovative Pool to assist moving young people out of residential aged care although early discussions have taken place around proposals in the ACT, South Australia and Victoria.¹⁴¹

139 *Submission* 160, p.15 (NAYPINH).

140 *Committee Hansard* 26.4.05, p.74 (VBIRA).

141 *Submission* 191, p.37 (DoHA).

4.114 The Department concluded:

While the Department of Health and Ageing is seeking to address the issue of younger people with disabilities inappropriately placed in residential aged care in a limited way through the Aged Care Innovative Pool, the main structural vehicle for change is the CSTDA. Since the CSTDA is managed by the Department of Family and Community Services, officers from the Department of Health and Ageing are working with their colleagues in the Department of Family Services via the Aged Care – Disability Joint Policy Forum, which aims to improve the co-ordination of policy issues around the aged care – disability interface, on this important issue.¹⁴²

4.115 The Victorian Government stated it was seeking to progress small scale jointly funded initiatives through the Pool and that the result can inform future development of jointly funded options. However, the Government went on to state that 'the lack of flexibility and sustainability in the CIP Program is limiting opportunities to develop long-term care alternatives.'¹⁴³

4.116 NSW Health argued that the Innovative Pool presented a possible mechanism to develop alternative models for supporting younger people in aged care facilities but stated 'the current timing and funding restrictions applied to these places by the Commonwealth would first need to be reconsidered'.¹⁴⁴ Other witnesses also noted that the Innovative Pool is not designed to provide on-going or longer term services with Melbourne Citymission stating that it had concerns 'about raising expectations of accommodation and service options that have no long term funding base because sources are non-recurrent'.¹⁴⁵

4.117 The MS Society of Australia, which obtained funding for Carnegie House in Melbourne, saw problems in the design of the Innovative Pool which hampered groups from doing likewise:

The other reason why we cannot replicate it in every state is the design of the innovative pool. That again is part of the reason why it took two to three years to get that house going. I think you have heard evidence from other people who have put in innovative pool proposals to their state government and they have not actually made it across the border to Canberra. The innovative pool is a good concept that has been absolutely tortured by the bureaucrats into a scheme that is almost unworkable because it needs to get through the state sausage machine before the Commonwealth can adjudicate on it. If you fail at that step, the Commonwealth does not even see the good idea.¹⁴⁶

142 *Submission* 191, p.37 (DoHA).

143 *Submission* 180, p.8 (Victorian Government).

144 *Submission* 202, p.13 (NSW Health).

145 *Submission* 61, p.10 (Melbourne Citymission).

146 *Committee Hansard* 26.4.05, p.62 (MS Society Australia).

4.118 The MS Society Victoria provided more evidence on the problems with accessing the Pool for the Carnegie House project and pointed to prescriptiveness of the Aged Care Act and the policy and funding imperatives of state disability services. It stated that:

Some States reportedly refused to take part out in the Pool due to the rigidity of the guidelines, and the lack of incentive. But with some states expressing an unwillingness to participate, providers in those states saw no future in putting resources into service development given the projects would not be supported.

This closed off any opportunity for young people to benefit from the program.¹⁴⁷

4.119 Another barrier for the States is the lack of access to ongoing funding: a facility may be established but the States may not be able to sustain in the long term.

4.120 The Society also noted that the time constraints on the Pool made the State Governments reluctant to participate. It stated that if the Pool were restructured so that there was joint funding, 'you could have 10 or 12 [new facilities] in every state very quickly. The technology, the models and the skills of assessment and service delivery are there.'¹⁴⁸

Commonwealth State Territory Disability Agreement (CSTDA)

4.121 The Commonwealth State Territory Disability Agreement (CSTDA) provides the national framework for the provision of government support to specialist services for people with severe and profound disabilities. The Commonwealth is responsible for planning, policy setting and management of specialised employment assistance. The State and Territory Governments have similar responsibilities for accommodation support, community support, community access programs such as day programs and respite. Support for advocacy, information and print disability is a shared responsibility.

4.122 Bilateral agreements between the Commonwealth and each jurisdiction covering agreed areas of mutual concern have been established. In all States and Territories, except the Northern Territory, younger people in residential aged care has been identified as an area to be addressed. Work plans developed under the agreements aim to address both accommodation options and access to services for younger people with a disability living in residential aged care.¹⁴⁹ The Department of Family and Community Services (FaCS) stated:

One of the key projects of national disability administrators is to specifically look at the care needs of those younger people who are in

147 *Submission* 175, p.17 (MS Society Vic).

148 *Committee Hansard* 26.4.05, p.62-63 (MS Society Australia).

149 *Submissions* 191, p.37 (DoHA); 202, p.12 (NSW Health).

nursing homes. Our intention, as part of that process, is to encourage the states and territories to provide care for those people within their own environments in accommodation support services and, most importantly, to try and minimise the need for younger people with disabilities to go into aged care nursing homes in the future.¹⁵⁰

FaCS indicated that it was 'taking a lead role and is currently working cooperatively with relevant State and Territory departments through the multilateral and bilateral agreements under the CSTDA to explore alternative support models for younger people in residential aged care facilities'.¹⁵¹

4.123 However, ACROD argued that 'while the bilateral agreements linked to the CSTDA do intend to progress the issue of younger people inappropriately housed in residential aged care, they give it no urgency: unless given a higher priority, it is unlikely to be resolved by the conclusion of the Agreement'.¹⁵²

4.124 The Victorian Brain Injury Recovery Association also stated:

...in the first CSTDA there was a timetable that had to be followed by the States to meet the federal requirements. That has never been followed, and the Commonwealth has continued to accept [that] year after year – we are now into the 15th year. And so the nursing homes are clogging up with people who have been accepted compassionately by the Commonwealth. We are not criticising the Commonwealth for doing it, except to say that, if the Commonwealth is going to continue and persist in allowing, please provide the funds to allow providers to give the care that is necessary.¹⁵³

4.125 The MS Society of Victoria similarly stated 'government's support the aspirations of people with a disability, and have endorsed community living and choice as core principles of disability services, however in the case of young people in nursing homes, practical delivery of this rhetoric through the CSTDA has been miserable'.¹⁵⁴

4.126 ACROD stated that the incidence of young people inappropriately housed in nursing homes is an example of 'the suspicion about cost shifting which so inhibits development of sensible policies in these areas' and that:

There are some good statements of intention within cross-government agreements. The Commonwealth State Territory Disability Agreement includes some statements of intention around improving the linkages across government, and there are some commitments to improve the interface between aged care and disability services, but in the formation of that

150 Senate Community Affairs Legislation Committee, *Estimates*, 30.5.05, p.CA89.

151 *Submission* 168, p.2 (FaCS).

152 *Submission* 26, p.4 (ACROD).

153 *Committee Hansard* 26.4.05, p.78 (Victorian Brain Injury Recovery Association).

154 *Submission* 175, p.12 (MS Society of Victoria).

agreement the federal Department of Health and Ageing is hardly involved and has no sense of ownership over the outcomes of that agreement.¹⁵⁵

4.127 The Gippsland Carers Association also commented on cost and stated:

The overwhelming cost of the 5/6 bed group home option (\$100,000 per bed in Victoria) compared to the cost of aged care residential services is a further disincentive for states and territories to hold up their end of the CSTDA bargain.¹⁵⁶

4.128 NAYPINH stated that the State systems are largely fulfilling their obligations under the CSTDA for those with intellectual and other congenital disabilities. However, the State disability systems 'struggle with the reality of developing and sustaining services to people with acquired disabilities who have additional rehabilitation or nursing needs'. This group includes people with ABI, and neurological conditions such as MS. The NAYPINH commented that 70 per cent of people accessing services through the CSTDA have an intellectual disability, while over 80 per cent of young people in aged care facilities have an acquired disability. NAYPINH concluded that 'this shows the lack of capacity of the CSTDA sector to plan and provide for people with an acquired disability' and pointed to the under representation of acquired neurological conditions in the disability accommodation sector that is dominated by intellectual disability and congenital conditions. It argued that congenital disabilities have more predictable outcomes that makes the planning and resources of supports and services simpler than for acquired disabilities.¹⁵⁷

4.129 The NAYPINH recommended that young people in aged care facilities be made a priority under the CSTDA and that disability funds can follow young people with complex needs into aged care nursing homes and provide for their different support needs while they live there.¹⁵⁸

4.130 NAYPINH went on to note that under the CSTDA, it is agreed that the provision of 'services with a specialist clinical focus' are excluded from the agreement (Section 5(4)(b)). While noting that the term is not defined, 'it is assumed that at the time of agreement, it was most probably meant to refer to acute, sub acute health services and rehabilitation'. However, NAYPINH commented that:

...in practice, it has given effective permission for the States to avoid responsibility for young people needing what they call 'nursing home level of care'. Every State jurisdiction is trying to resist providing accommodation services with a nursing component, which is the nub of the problem for the YPINH group.¹⁵⁹

155 *Committee Hansard* 11.2.05, p.50 (ACROD).

156 *Submission* 62, p.2 (Gippsland Carers Association).

157 *Submission* 160, p.10; Supplementary Submission p.4 (NAYPINH).

158 *Submission* 160, p.11 (NAYPINH).

159 *Submission* 160, Additional Information 30.5.05, p.1 (NAYPINH).

4.131 NAYPINH concluded that the States thus have the backing of the CSTDA itself to take up their position, saying it is a Commonwealth responsibility to provide services to this complex needs group, while the Commonwealth tries to use the same agreement to press the responsibility back to the States:

The practical effect of this clause serves to both neutralise the current Commonwealth argument; and to underline the need for a discrete approach to deal with the YPINH problem...The various bilateral agreements about YPINH are simply not strong enough to overcome this inherent flaw in the CSTDA framework. The States are simply not accountable to deliver the solution through the CSTDA.¹⁶⁰

The NAYPINH called for the urgent redrafting of clause 5 of the CSTDA with appropriate financial agreements and accountabilities.

4.132 The MS Society of Victoria also commented on this aspect of the CSTDA:

The almost total lack of availability of nursing care in disability services is something that must be addressed by the CSTDA administrators...If nursing could be included in the CSTDA suite, it would serve to significantly reduce the transfer of people from CSTDA to aged care.¹⁶¹

4.133 Another matter highlighted by NAYPINH was the lack of involvement of the Commonwealth Department of Health and Ageing. It noted that DoHA is the largest funder of disability services for young people in aged care facilities at the Commonwealth level and as such 'needs to have a direct role in the negotiation and monitoring of the CSTDA agreements going forward. NAYPINH recognised that DoHA is involved indirectly through interdepartmental liaison groups, 'this is inadequate and cannot replace direct input and accountability'.

4.134 The Disability Services Commission Western Australia stated that there is a lack of information on the needs and profile of young people in aged care facilities and noted that it is important to recognise that 'not all young people in nursing homes fall within the CSTDA target group. Some of these people may be chronically ill, recovering from an illness or accident, require palliative care, or have aged care needs due to premature ageing.'¹⁶²

4.135 NSW Health stated:

The Bilateral Agreement is a significant and essential step to finding long lasting and effective solutions. However, the work required will take some time and will not result in immediate changes for individuals. It is, therefore, essential that younger people living in nursing homes are not disadvantaged in the interim. As an intermediate step, ways to improve access to additional support services for younger people living in nursing

160 *Submission* 160, Additional Information 30.5.05, p.2 (NAYPINH).

161 *Submission* 175, p.15 (MS Society of Vic).

162 *Submission* 192, p.2 (Disability Services Commission, WA).

homes are being investigated by DADHC, including access to a range of services from mixed funding sources. This will require cooperation across both the disability and aged care sectors.¹⁶³

4.136 NSW Health pointed to the enormous problem of supporting disabled people in the community:

My understanding is that that would be happening. The problem is – and this is a very real problem – is around whether it is sustainable. I am not here to speak for DADHC. But there are increasing numbers of individuals being cared for in the community by DADHC where in some cases the annual cost of care is up to \$900,000. There are very many individuals whose annual cost of care is over \$500,000...Per person per year. Because they require 24-hour personal care by individuals it is an enormously significant impost. As I say, the question is, despite the desirability of the best model of care – the ethical considerations and all those things – as there are increasing numbers of people with profound levels of disability surviving, there is a very real question as to whether the model is sustainable.¹⁶⁴

4.137 Concerns were also raised about future needs. Witnesses stated that demand for services will continue to increase as people, many with very high needs, may now survive a catastrophic event through advances in medicine. Medical advances and improved health care systems also mean that people with degenerative neurological conditions are surviving longer and enjoying a better quality of life. The NAYPINH concluded that:

The result is that the number of people with acquired disabilities in Australia is growing and existing disability systems – established to deal with the comparative predictability of congenital disabilities – are ill-prepared to deal with the complexity and more intensive needs of young people with acquired disabilities.¹⁶⁵

4.138 The MS Society of NSW also voiced concern and stated:

The thing that strikes me about the whole sector is that there is no recognition of unmet need. There is no planning forward in terms of the next wave of people with disabilities. As I alluded to in my opening address, we have identified some 300 people with MS that will need further care if there is a change in their current support networks. That is going to happen. There is no recognition of that; there is no forward planning in those areas and there is no understanding of unmet need.¹⁶⁶

163 *Submission 202*, p.13 (NSW Health).

164 *Committee Hansard 19.8.04*, p.56 (NSW Health).

165 *Submission 160*, Supplementary Submission p.4 (NAYPINH).

166 *Committee Hansard 19.8.04*, p.17 (MS Society of NSW).

4.139 Demand will also increase with the rise in disability that accompanies an ageing population. NAYPINH submitted that in NSW, where there is significant unmet need, some non-government organisations have estimated that there are over 7000 people with disability in NSW in need of supported accommodation and around 4000 ageing carers of young people with disability who require, or will soon require, support. However, NAYPINH went on to state that this is seen as an underestimate with over 10 000 currently on the Victorian and NSW waiting lists.¹⁶⁷

4.140 In relation to the CSTDA, FaCS stated that:

Whether it is a CSTDA accommodation support service or an aged care place that is provided outside the CSTDA, I think it is fair to say that the assumption in both cases is that the service is meeting the needs of the person...if a person is receiving an accommodation support service or a nursing home service, those service providers are meeting that person's need.¹⁶⁸

FaCS commented that there is no barrier in the CSTDA to anyone in a range of housing options from accessing a component of support out of CSTDA:

It is up to the States and Territory how it manages the expenditure of those funds on people with disabilities...They know they are responsible for the planning and policy setting. It is possible that the States are making decisions about what they see as relative priorities...As long as they spend the money they have committed to spend on people who are in the target group of the CSTDA, which are essentially people with disabilities, it is up to them what they spend that money on.¹⁶⁹

4.141 FaCS also commented on the provision of specialist clinical services. It noted that the intention of the clause is primarily aimed at separating what would be regarded as health interventions, such as mental health services, acute health treatment etc from the CSTDA as the CSTDA's purpose is to provide continuing day-to-day life needs. This provision arose as a result of the clarification of responsibilities in the first CSTDA agreement in 1991. FaCS stated:

...[people with disabilities] may need physiotherapy for their physical disability. They may need speech therapy for their communications needs. Beyond a very minor level, those therapy services and acute treatment type services are not considered to be part of the CSTDA...the purpose of the clause was very much around trying to draw a line between the purpose and scope of the CSTDA and the provision of health and allied health services that would generally be available to anyone in the community.¹⁷⁰

167 *Submission 160, Supplementary Submission p.7 (NAYPINH).*

168 *Senate Community Affairs Legislation Committee, Estimates, 30.5.05, p.CA86.*

169 *Senate Community Affairs Legislation Committee, Estimates, 30.5.05, p.CA87.*

170 *Senate Community Affairs Legislation Committee, Estimates, 30.5.05, p.CA88.*

4.142 FaCS concluded:

People with disabilities...are perfectly entitled to access the allied health services. The provision of those services is the responsibility of the State government along with the provision of accommodation support. Both are matters of State government funding and management. All we are trying to do in the CSTDA, by agreement, is make it clear that what is being funded. As the minister said, that does not stop a State putting together a package of services for a person which includes whatever physiotherapy and allied health services they need. It is simply a State decision and a State responsibility.¹⁷¹

Changes to funding arrangements

4.143 Witnesses argued that the current funding arrangements entrenched problems in access to services for those living in the community and hindered attempts to move young people out of aged care facilities. ACROD submitted that younger people would be better served if they were housed in the community but:

The principal barrier to this occurring is the disagreement between the Commonwealth and State governments about who has funding responsibility (and associated suspicion about cost shifting). The way forward requires a funding model that combines ongoing and indexed Commonwealth Health and Aged Care Funding and State Disability Services funding.

The younger people who reside in nursing homes often have high-level physical support needs or complex medical needs (requiring ventilator support and gastrostomy meals, for example). But the funding available to aged care services or to disability services is alone insufficient to support these younger people to live in the community. Funding formulae have failed to keep pace with the real costs of assisting people who have complex medical support needs.¹⁷²

4.144 ACROD advanced the view that in relation to those young people moving out of aged care facilities, the Commonwealth should allow the aged care funding that it provides for the aged care place to follow the person into the community. The funding would need to be indexed so it would increase in line with the cost of living and for the States to provide the difference between the Commonwealth funding and the amount required for the person to live in the community.¹⁷³ NCOSS also supported this approach and stated that 'this change would align service provision to these younger people with disabilities towards the current Commonwealth and State legislation which prefers people with disabilities to be offered the same life chances eg accommodation, opportunities etc as people without disability of the same age'.¹⁷⁴

171 Senate Community Affairs Legislation Committee, *Estimates*, 30.5.05, p.CA88.

172 *Submission 26*, p.4 (ACROD).

173 *Committee Hansard* 11.20.5, p.53 (ACROD).

174 *Submission 204*, p.11 (NCOSS).

4.145 YPACA supported individual funding so that the funding remained with the person. YPACA went on to note that individualised funding is seen by people with disabilities as being a step towards independence.¹⁷⁵ Australian Home Care Services stated that individual funding means that 'we do not have the notion that we put people in a place and they stay there forever. Rather, it means that we have a continual planning process, that we open the system up and that we can step people up and down and move them to where they will receive the support they need'.¹⁷⁶

4.146 NCOSS recommended that younger people in aged care facilities could be transferred to an Extended Aged Care at Home (EACH) or Community Aged Care Package (CACP) whereby the funding is used to support the person either at home or in a small group situation. Community care programs are discussed later in this report.

4.147 The Victorian Government noted that although younger people with disabilities are able to access services through the residential aged care program, 'there are funding and policy issues that affect service provision for this group'. The Victorian Government stated that it is engaged with the Commonwealth to progress these issues and indicated that 'the Victorian Government has consistently argued that while it accepts its responsibilities under the Commonwealth States and Territories Disability Agreement (CSTDA) people with disabilities who require residential aged care services are not readily provided for under the Agreement'. The Government concluded that it strongly favoured the joint development of sustainable and long-term solutions with the Commonwealth.¹⁷⁷

4.148 Evidence to the Committee pointed to significant barriers in establishing accommodation options due to fragmentation of the system. While there have been successes where the accommodation model is appropriate, where the funding has been put in place and where adequate services have been available, the very small number is tangible evidence of the barriers in place. In NSW for example, evidence from the Liverpool BIRU indicated that the Department of Housing modified houses and that people like the Lions Club were very interested in getting a property and then being able to renovate it but 'those discussions can only go so far when you cannot actually guarantee that the person that is moving into the house will have the support'.¹⁷⁸

4.149 There was continued emphasis during the Committee's hearings on the successes in Western Australia and Victoria of the independent living housing projects as being a result of a coordinated approach:

The success in Western Australia is probably attributable to the fact that there was a project. They got all of the stakeholders together – the Commonwealth, the Disability Services Commission, Housing and perhaps

175 *Committee Hansard* 18.3.05, p.47 (YPACA).

176 *Committee Hansard* 26.4.05, p.66 (Australian Home Care Services).

177 *Submission* 180. p.7 (Victorian Government).

178 *Committee Hansard* 11.3.05, p.20 (Liverpool BIRU).

Health. They dedicated money and gave a mandate to this project to complete the job. They were the key success factors.¹⁷⁹

4.150 Cyrill Jewell House in Victoria is another example where all stakeholders came together. The MS Society of Victoria stated that 'it is a model that shows that a cross jurisdictional funding arrangement can work without threatening the integrity of each sector and actually working in the interests of young residents'. The Society concluded:

It is a promising development, and is the only effective way forward to resolve the issue, since the YPINH group have dual eligibility for both disability and aged care, so both jurisdictions must work to design the solution.¹⁸⁰

4.151 Another matter raised in evidence was the level of nursing care a person may require. The MS Society of Victoria stated that this was the 'defining issue' as disability services seem to be unwilling or unable to consider the provision of nursing as part of disability services.¹⁸¹ The parents of one young person in an aged care facility also commented that they had been told that there was no other option for their son as 'there is no nursing care for his needs in the disability system'.¹⁸²

4.152 Melbourne Citymission concluded:

Within an existing fragmented service system, there is a need for cross-sector partnerships to develop a co-ordinated approach across the acute sector, sub-acute rehabilitation services, disability services and aged care. As a result, co-operation is needed across all levels of government. Inflexibility or inadequate funds in one area frequently leads to cost-shifting into another area. In such an environment, the needs of the individual can become a secondary consideration.

Cross government collaboration is required to assist with the development of an integrated, cross sector policy response to assessment and placement of people requiring high levels of care. Such a policy might include, 'a short term role for nursing homes in emergencies, assessment, slow stream rehabilitation and transition to other accommodation settings (Fyffe et al, 2003:60) rather than being seen as 'the end of the line' where no future alternatives exist. In addition to preventing long term placements in the first place, it is also important to work to develop pathways out of such placements for those currently in inappropriate aged care facilities.¹⁸³

179 *Committee Hansard* 26.4.05, p.66 (MS Society Australia).

180 *Submission* 175, p.3 (MS Society of Vic).

181 *Submission* 175, p.15 (MS Society of Vic).

182 *Committee Hansard* 26.4.05, p.91 (Mrs M Nolan).

183 *Submission* 61, p.10 (Melbourne Citymission).

4.153 The NAYPINH argued that there was a need for a systemic change if sustainable solutions are to be developed and called for all levels of government to take on the responsibility to do so. It stated that the expectation that the States will solve the young people in aged care facilities problem on their own is unrealistic:

In many ways, it is also undesirable as neither the CSTDA nor other programs, including the Innovative Pool, contain satisfactory accountability mechanisms to ensure targets are set and met; money is dedicated and delivered to YPINH; or that joint responsibility is defined. These three preconditions must be met before we can confidently move forward and the problem of accountability that, for YPINH remains a very real one, is dealt with.¹⁸⁴

4.154 NAYPINH went on to argue that the existing policy frameworks and jurisdictional boundaries cannot lend themselves to resolving the problem quickly because 'there is no incentive or rationale to do so'. The Commonwealth needs to take on a leadership role and be financially committed to developing and maintaining supported accommodation options for young people in aged care. NAYPINH concluded:

A major step towards the solution is a multi jurisdictional targeting of the YPINH issue through a national taskforce linked to the CSTDA.¹⁸⁵

4.155 Such a taskforce would involve all jurisdictions to oversight and implement the supported accommodation options young people need and include:

- funding provided by the Commonwealth and States and Territories for each young person transferring from residential aged care to supported accommodation elsewhere. The funding arrangement would be recurrent and be maintained for the individual's lifespan;
- where young people choose to remain in residential aged care the State or Territory concerned would fund the delivery of all support services and the Commonwealth would continue to fund the bed costs;
- the States and Territories would provide capital and funds for any costs associated with adapting or modifying existing accommodation options;
- the States and Territories would provide a seeding grant for each young person living in residential aged care or in community based supported accommodation to assist with equipment needs and any modifications needed to buildings;
- the Commonwealth and States and Territories to provide funding for transitional programs;

184 *Submission 160, Supplementary Submission, p.8 (NAYPINH).*

185 *Submission 160, Additional Information 30.5.05, p.2 (NAYPINH).*

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- in the first instance, funding should be provided to allow 700 young people to be offered supported accommodation options each year over a five year period; and
 - funding to follow the individual.

Council of Australian Governments

4.156 The Council of Australian Governments (COAG) meeting on 3 June 2005 agree that there was room for governments to discuss areas of improvement in the Australian health system. The COAG Communiqué stated that 'governments recognised that many Australians, including the elderly and people with disabilities, face problems at the interfaces of different parts of the health system. Further, governments recognised that the health system can be improved by clarifying roles and responsibilities, and by reducing duplication and gaps in services'. Included in the ways in which the health system could be improved were:

- simplifying access to care services for the elderly, people with disabilities and people leaving hospital; and
- helping younger people with disabilities in nursing homes.¹⁸⁶

4.157 COAG agreed that Senior Officials would consider these ways to improve Australia's health system and report back to it in December 2005 on a plan of action to progress these reforms. It was also agreed that where responsibilities between levels of government need to change, funding arrangements would be adjusted so that funds would follow function.

Conclusion

Our concern, quite frankly, is that we will run out of puff unless there is something that happens at a higher decision-making level than we can marshal...We are trying to be solutions based, not problem identifiers. There are problems out there – we know it and you know it. We are saying that there is a range of ways in which we can solve this. Our challenge is not to see it for the one-offs. Let us take the higher calling here and the high moral ground and, across all of our areas of politics and government, say, 'This needs to be solved.' We do have some solutions – let us solve it. We can identify the solutions, but again it needs to be taken at a much higher level of decision-making. That is why we believe today is critical. This is a watershed for us.¹⁸⁷

4.158 One of the most difficult aspects of this inquiry has been the issue of young people in aged care facilities. The Committee is strongly of the view that the accommodation of young people in aged care facilities is unacceptable in most

186 Council of Australian Governments, *Communiqué*, 3 June 2005, <http://www.coag.gov.au/meetings/030605/>

187 *Committee Hansard* 26.4.05, p.62 (MS Society Australia).

instances. Young people should not be in aged care facilities as these facilities and services are designed for, and respond to, the needs of the frail elderly. Elderly residents have care needs, health needs and social needs which are quite different from young people.

4.159 Aged care facilities are not places which readily enable a young person to socialise with family and friends. They are not places where young people can listen to their music or have their own space. They are generally inward-looking places with little interaction with the greater community as would benefit, and is needed by, a young person.

4.160 Evidence suggests that the environment of an aged care facility significantly reduces the ability of an individual to work towards a future, redevelop life skills and re-establish social and inclusive networks. This is particularly the case for young people with acquired brain injury. For those young people with, for example, degenerative disease, aged care facilities may not provide the specific complex health support or palliative care required.

4.161 The Committee therefore considers that there is an urgent need to provide alternative services for young people in aged care facilities particularly those aged less than 50 years. The Committee considers that programs must also be in place to ensure that more young people are not placed in aged care facilities inappropriately. The Committee is of the view that the way forward is for all jurisdictions, the Commonwealth and the State and Territory Governments, to work cooperatively to identify viable solutions.

4.162 Having come to the conclusion that aged care facilities are not appropriate for young people, the Committee was mindful of the fact that in certain circumstances there may be no alternative accommodation options. This is particularly the case in rural and regional areas where there are fewer services to support young people in the family or the community. In such cases, families may choose aged care accommodation, even with a lesser level of services, to keep their young person close to them and their community of origin.

4.163 In order to achieve the aim of moving young people out of aged care facilities, the fundamental requirement is for the provision of appropriate services in the community that meet the needs of each person. The Committee has visited successful models of supported accommodation and has noted the outcome of the Young People in Nursing Homes project in Western Australia. The Western Australian project resulted in 95 people accessing a variety of accommodation arrangements to meet their needs.

4.164 The Committee does not consider that it is of benefit to be prescriptive about models of accommodation and service delivery. The situation of each person is different: type and level of disability; family circumstance; and geographical location. What is evident to the Committee is that there must be a range of accommodation options for young people who are moving out of aged care facilities with matching

provision of services. Accommodation options may range from the family home to specialised group cluster housing. Which ever it is, appropriate services with adequate funding are the basis of success as is the willingness of all stakeholders to work together to provide innovative solutions.

4.165 The success of projects under the Innovative Pool and in Western Australia underscores the need for a co-ordinated and collaborative approach. Unfortunately, it appears that the main push for change to the provision of services by government has been left up to individual interest groups. A solution to moving young people out of aged care facilities needs whole of government commitment and coordination of government and non-government funds and expertise.

4.166 The Committee has noted that helping young people with disabilities in nursing homes is now to be considered by Senior Officials for the Council of Australian Governments. The Officials are to report to COAG in December 2005. The Committee considers that this will be an important step in improving access by young people in aged care facilities to other support services. However, the Committee considers that solutions already exist and that the Senior Officials should concentrate their efforts in extending those models which have already proven to be viable.

Recommendation 22

4.167 The Committee is strongly of the view that the accommodation of young people in aged care facilities is unacceptable in most instances. The Committee therefore recommends that all jurisdictions work cooperatively to:

- **assess the suitability of the location of each young person currently living in aged care facilities;**
- **provide alternative accommodation for young people who are currently accommodated in aged care facilities; and**
- **ensure that no further young people are moved into aged care facilities in the future because of the lack of accommodation options.**

Recommendation 23

4.168 The Committee notes that the Council of Australian Governments has agreed that Senior Officials are to consider ways to improve Australia's health care system, including helping young people with disabilities in nursing homes, and to report back to COAG in December 2005 on a plan of action to progress these reforms. The Committee recommends that the Senior Officials clarify the roles and responsibilities of all jurisdictions in relation to young people in aged care facilities so as to ensure that:

- **age-appropriate accommodation options are made available; and**
- **funding is available for the provision of adequate services to those transferring out of aged care facilities.**

The Committee supports every endeavour to reach a positive outcome.

Recommendation 24

4.169 That the Senior Officials' report to the Council of Australian Governments include:

- **support for a range of accommodation options based on individual need;**
- **ways in which the successful accommodation and care solutions already in place can be extended to other jurisdictions;**
- **identification of barriers to the successful establishment of accommodation options and provision of adequate support services by all levels of government; and**
- **identify a timeframe for the establishment of alternative accommodation options and the transfer of young people out of aged care facilities.**

Recommendation 25

4.170 That the Commonwealth and State and Territory Governments work cooperatively to ensure that any barriers to accessing funds available under the Innovative Pool are removed so that the desired objective of this initiative in providing alternative accommodation options for young people in aged care facilities is met.

4.171 The Committee recognises that, in rare instances, young people may choose to remain in an aged care facility. In such cases, the Committee considers that it is necessary to ensure that there are adequate services that address not only accommodation needs, but also specialist health needs, allied health support, equipment and psychosocial needs. Particular attention is required to ensure that young people are encouraged to maintain social links and to feel part of the wider community.

4.172 The Committee considers that in order to achieve the level of services required by young people in aged care facilities, cooperation by the Commonwealth and State and Territory Governments is required. The Committee considers that governments will need to examine the assessment tool used to evaluate the complex care needs of young people in aged care facilities. Cooperation and collaboration will also be necessary to establish mechanisms to provide rehabilitation and other disability-specific health and support services and ways to ensure that those caring for young people in aged care facilities have the appropriate skills to meet complex care needs.

Recommendation 26

4.173 The Committee recognises that in rare instances, a young person may choose to remain in an aged care facility. In such circumstances, the Committee recommends that the Commonwealth and the States and Territories work cooperatively to reach agreement on:

- **an assessment tool to address the complex care needs of young people in aged care facilities;**

-
- **mechanisms, including a funding formula, to provide rehabilitation and other disability-specific health and support services, including specialised equipment; and**
 - **ways to ensure that the workforce in aged care facilities caring for young people has adequate training to meet their complex care needs.**

Recommendation 27

4.174 That the Department of Health and Ageing collect data on young people in aged care facilities by disability type.

4.175 The Committee has also noted the growing number of older carers of disabled young people. While a working party of officials has been established to provide advice on assisting ageing carers and the Commonwealth has provided funding to be matched by State and Territory Governments for respite care, the needs of carers are becoming acute. The Committee considers that the investigations being undertaken by the working party must be expedited in order to identify ways for the needs of the family members of older carers to be better met.

Recommendation 28

4.176 That the Commonwealth and State and Territory Governments give priority to the efforts of the Working Party established in November 2004 to examine succession planning for ageing carers of children with disabilities and appropriate support for respite for carers.

CHAPTER 5

FUNDING FOR RESIDENTS WITH SPECIAL NEEDS

Current funding arrangements do not appropriately support the provision of residential aged care services to older people presenting with special needs including dementia, residents with challenging behaviours and complex care needs. Funding arrangements support a standard service response to all needs with some special needs not being met, such as older people needing mental health care who experience access restrictions to generic residential aged care.¹

5.1 Residents in aged care facilities with special needs, including those with dementia, mental illness and requiring palliative care, require additional services and support. The staff providing for their care also require skills to ensure that they have the ability to manage complex care needs. This chapter looks at the care needs of these groups, the findings of the Hogan Review² and current funding arrangements, including recent Commonwealth initiatives.

Funding arrangements

5.2 The Hogan Review provides a detailed examination of funding arrangements for residential aged care including special needs groups. The following is a brief overview.

5.3 The Commonwealth provides subsidies to providers of aged care. Fees are also paid by individuals. The Resident Classification Scale (RCS) provides the basis on which the subsidies are paid for each resident. The subsidy is calculated as follows:

- a basic subsidy determined by the resident's classification under the RCS; plus
- any primary supplements; less
- any reductions in subsidy resulting from the provision of extra services, adjusted subsidies for government (or formerly government) owned aged care homes or the receipt of a compensation payment; less
- any reduction resulting from income-testing of residents who entered residential care on or after 1 March 1998; plus
- other supplements, including the pensioner supplement, the viability supplement and the hardship supplement (which reduces charges for residents who would otherwise experience financial hardship).³

1 *Submission 180*, p.8 (Victorian Government).

2 Hogan WP, *Review of Pricing Arrangements in Residential Aged Care, Final Report*, Canberra, 2004.

3 Hogan Review, pp.201-08.

- 5.4 At the time of the Hogan Review, primary supplements were provided for:
- concessional and assisted residents: for those who are unable to afford to pay an accommodation bond or charge;
 - respite: paid to offset the higher administration and care costs of respite care;
 - charge exempt resident: for those who were in an aged care facility on 30 September 1997 and who move to another facility where they would otherwise be eligible to pay an accommodation charge;
 - oxygen and enteral feeding: for those requiring on-going oxygen or enteral feeding;
 - payroll tax; and
 - transitional resident supplement.

The hardship supplement provides for residents who experience difficulty in paying for their care. It may be paid for specific classes of resident or for individuals who apply for a hardship determination.

5.5 The Department of Health and Ageing (DoHA) stated that a significant component of the current RCS focuses on the additional effort needed to assist people who have problems of cognition or who need additional care around the management of problem behaviours. Funding for people with dementia was estimated to be \$2.3 billion in 2004-05.⁴

Hogan Review

5.6 In reporting on the arrangements for funding the care needs of special needs groups, the Hogan Review stated that it had received evidence that there were expectations that more complex care would be provided by aged care facilities. This included complex pain management, palliative care, wound management, dialysis and tracheotomy care. The Review also noted that providers questioned the adequacy of the subsidies payable for people with a range of specific care needs including dementia and stroke and people from diverse or disadvantaged backgrounds.⁵ The Hogan Review examined the needs for those residents with dementia, those requiring palliative care, those in remote and rural areas, the elderly homeless and people from Aboriginal and Torres Strait Islander communities and culturally and linguistically diverse backgrounds.

5.7 The Review supported the approach for basic subsidies to be determined on level of need for care, supplemented by additional payments for extraordinary care needs that add significantly to the cost of care. The Review recommended:

Recommendation 6	Funding supplements
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4 *Submission* 191, p.38 (DoHA).

5 Hogan Review, p.212.

The arrangements through which supplements are paid for the provision of oxygen and enteral feeding should be extended to other specific care needs or medical conditions.

These specific care needs could include:

- (a) short-term medical needs, such as IV therapy, wound management, intensive pain management and tracheostomy;
- (b) specific care needs, such as for dementia sufferers exhibiting challenging behaviours or for residents requiring palliative care; and
- (c) care needs of people from diverse or disadvantaged backgrounds such as the homeless elderly and indigenous Australians.

The rate of payment of any new supplements should reflect the incremental increase in the cost of providing the appropriate treatment and/or level of care.⁶

Government response

5.8 As part of the 2004-05 Budget, the Commonwealth announced its response to the recommendations of the Hogan Review. These include new residential care supplements to be introduced in 2006 'to better target assistance to people with higher care needs by supporting the provision of care to people with dementia exhibiting challenging behaviours and people requiring complex palliative nursing care'. An additional \$11.6 million over the next four years was provided to strengthen culturally appropriate aged care. It was noted that care needs of people from diverse or disadvantaged backgrounds are supported by a number of Australian Government programs.⁷ The cost of the new supplement 'will be absorbed from within existing resources'.⁸

5.9 The Commonwealth also stated that it considered that 'extending supplements to other conditions or circumstances would add unnecessary complexity to the payment system and administration'.⁹

Other Commonwealth programs

5.10 The Commonwealth also supports a number of programs which target special needs, particularly people with dementia, including Home and Community Services, Community Aged Care Packages and Extended Aged Care at Home packages. A range of targeted dementia services include the Dementia Education and Support Program, the National Dementia Behaviour Advisory Service, the Early Stage

6 Hogan Review, p.282.

7 The Hon Julie Bishop, Minister for Ageing, *Investing in Australia's Aged Care: More Places, Better Care*, May 2004, p.22.

8 *Budget Measures 2004-05*, Budget Paper No.2, p.190.

9 *Australian Government's Response to the Review of Pricing Arrangements in Residential Aged Care*, p.2.

Dementia Support and Respite Project, Carer Education and Workforce Training, and Psychogeriatric Care Units.¹⁰

5.11 In January 2005, Australian Health Ministers jointly agreed to the development of a National Framework for Action on Dementia. The Framework will 'provide an opportunity to co-ordinate a strategic, collaborative and cost-effective response to dementia across Australia'. Consultations with peak bodies, families and carers are to take place to develop 'a shared national vision for action on dementia'. A national forum will be held in July 2005. The consultations will lead to the development of a draft National Framework to be considered by Australian Health Ministers in November 2005.¹¹

5.12 The Commonwealth has also made dementia a National Health Priority with a \$320.6 million package over five years targeting better prevention, treatment and care. In February 2005, funding of \$52.2 million over four years for the first component of the package was announced for additional research, improved care and early intervention programs. In the 2005-06 Budget funding of \$225.1 million over four years was provided for 2 000 new dementia-specific Extended Aged Care at Home places. Funding of \$25 million over four years was also provided for dementia training for up to 9 000 residential aged care workers and 7 000 people in the community who come into contact with people with dementia, such as police, emergency services and transport staff.¹²

5.13 DoHA noted that, in relation to mental health, the National Mental Health Plan 'calls for improved cooperation between the mental health and aged care sectors to ensure that Australians experiencing a mental disorder receive the best possible care. The delivery of mental health services, however, is constitutionally the responsibility of individual State and Territory Governments'.¹³

5.14 The Commonwealth's Ethnic Aged Care Framework seeks to improve partnerships between aged care providers, culturally and linguistically diverse communities and the Department of Health and Ageing and ensure that the special needs of older people from culturally and linguistically diverse backgrounds are identified and addressed. The Commonwealth also funds the Partners in Culturally Appropriate Care initiative under the Framework. This provides funding to organisations in each State and Territory which help to link culturally diverse communities with aged care providers to develop more culturally sensitive services and provides cross-cultural training for staff of residential age care services.

10 *Submission 191*, p.12 (DoHA).

11 DoHA, *National Framework for Action on Dementia Consultation Paper*, <http://www.health.gov.au/internet/wcms/publishing.nsf/Content/ageing-dementia-nfad.htm>

12 DoHA, *Ageing Factsheet 1 – Helping Australians with dementia, and their carers – making dementia a National Health Priority*, 10 May 2005.

13 *Submission 191*, p.39 (DoHA).

Responses to current funding arrangements

5.15 The difficulties of providing residential aged care for people with special needs are well documented.

5.16 The provision of services for the very large, and growing, number of people with dementia has been a significant problem. There was evidence that it was difficult to place people with dementia in aged care facilities which provide adequate levels of care. Witnesses pointed to the lack of dementia-specific funding and the failure of the RCS to adequately capture behavioural problems as the causes of the lack of places for those with dementia.¹⁴ The Office of the Public Advocate Qld stated:

[The RCS] is seen as not adequately recognising the support needs of people who have behavioural challenges, especially people with dementia and psychiatric illnesses. Although many of these people do not have high levels of personal or nursing care, the intensity in nature of their needs means that they require more personalised attention because of the impact of their behaviour on themselves and other residents.¹⁵

5.17 The Australian Society for Geriatric Medicine stated that current funding arrangements are 'extraordinarily documentation intensive but fail to generate a useful care plan' and fails to adequately recognise the resources required for management of behaviours in intermediate stage dementia care and leads providers to pick and choose patients who are easier and better reimbursed.¹⁶ They also result in a financial disincentive for the provision of restorative care and rehabilitation and fail to provide any incentive to provide medical treatment on site rather than transfer residents with new medical problems to state funded hospitals. The Society concluded that:

Appropriate and expert behavioural management, rehabilitation, illness and injury prevention, and on site acute and sub-acute medical care would all be cost effective to the Australian community, and preferred by most residents and their families. Current remuneration of specialized medical services and organization of public hospital aged care services does not support the provision of this care within the Residential setting.¹⁷

5.18 The Benevolent Society argued that 'facilities for people with dementia and disturbed behaviour are structurally under funded and their operation is dependent on the commitment of organisations to carry heavy financial losses. This is not sustainable in the long term.'¹⁸

14 *Submissions* 193, p.14 (Queensland Government); 196, p.8 (Aged Care Qld); 200, p.7 (Tasmanian Government).

15 *Committee Hansard* 18.3.05, p.4 (Office of the Public Advocate Qld).

16 *Submission* 80, p.3 (Australian Society for Geriatric Medicine; see also *Submission* 92, p.3 (Southern Cross Care).

17 *Submission* 80, pp.3-4 (Australian Society for Geriatric Medicine).

18 *Submission* 187, p.3 (Benevolent Society); see also *Submission* 196, p.8 (Aged Care Qld Inc).

5.19 Witnesses welcomed the new funding supplement. The Queensland Government stated that the new funding supplement was 'an acknowledgement that the current RCS does not adequately address the needs of this growing subset of residents'. The Government went on to comment that the proposed three level model of basic funding with supplement for special needs clients 'should encourage providers to take these clients'.¹⁹

5.20 However, some witnesses argued that the additional funding may not be adequate to meet the care needs of people suffering from dementia and that careful development of the supplement will be required. ANHECA for example, commented that residential aged care is experiencing substantial growth in the number of cases of dementia amongst residents in high and low care. It is estimated that approximately 60 per cent of residents in residential care suffer mild to severe dementia. However, ANHECA stated that 'there has been no work undertaken to consider the real cost of providing residential services to those with dementia or with behavioural or other difficulties'.

5.21 ANHECA recommended that prior to the implementation of the dementia and palliative care supplement in July 2006, a substantial review needs to occur regarding the actual cost of providing such services. ANHECA commented that while the top subsidy payable to a level 1 resident in residential care is \$118 per day, the average payment for an acute sector palliative care service can be as high as \$430 per day:

There is great difficulty reconciling these two quite separate figures. It is essential therefore, for government to look at the true cost of providing an effective palliative care program and an effective dementia program and to incorporate that cost provision within any revised residential care subsidy framework.²⁰

5.22 COTA National Seniors argued that for the new measures to be effect, they need to include incentives for providers to offer quality dementia care including an improved mix of capital/recurrent funding, appropriate training for staff caring for people with dementia and support for innovation in care for people with dementia.²¹

5.23 The Tasmanian Government and other witnesses stated that the new supplements appear to be funded from existing funds and may therefore divert resources from meeting other needs. The Tasmanian Government also suggested that the use of supplements needs to be reconsidered in conjunction with the overall design of a more appropriate funding model.²² ACS Australia stated:

19 Submission 193, p.14 (Queensland Government).

20 *Submission* 74, p.12 (ANHECA).

21 *Submission* 174, p.13 (COTA National Seniors).

22 *Submissions* 200, p.7 (Tasmanian Government); 150, p.17 (VAHEC); 166, p.11 (CHA); 173, p.6 (ACS Australia); 196, p.8 (Aged Care Qld).

Currently the proposal is to meet those very high needs by the redistribution of the existing pool of resources, and that is a source of some concern to us and our members, that if you do that then there are necessarily going to be people who are currently receiving services or who would have received such services into the future who will miss out. In other words, it could be seen as a form of rationing residential aged care as well as a form of targeting residential aged care.²³

5.24 Concern was also voiced at the delay in introducing the proposed new funding model as this will mean that difficulties in funding places for the elderly with special needs will continue for some time.²⁴

Areas of unmet need

Specialised facilities for dementia

5.25 There was debate in the evidence as to the need for dementia specific facilities. Some witnesses commented that dementia is not a 'special needs' any more, and should be incorporated into mainstream care.²⁵ Other witnesses stated that it was extremely difficult to care for both the frail elderly and those with dementia in the same facility:

The situation for many dementia residents in Australia currently, certainly in Tasmania, is that they are in integrated models so that someone like me, who manages 74 beds and another 22 transition beds, is trying to manage people with wandering and sometimes gross behavioural disorders in with residents who are cognitively capable. That is totally unfair to both those with dementia and those without dementia.²⁶

5.26 Victorian Association of Health and Extended Care (VAHEC) stated that only 5 per cent of high care and 6 per cent of low care beds are dementia specific with the majority of dementia residents being placed in mainstream residential services. The Association stated that 'whilst the majority of these services cater extremely well for residents with dementia, it is obvious their needs can be better responded to and met in dementia specific facilities'.²⁷

5.27 It was argued that the lack of purpose built facilities for people with dementia may result in a number of problems:

23 *Committee Hansard* 26.4.05, p.2 (ACS Australia).

24 *Submissions* 193, p.15 (Queensland Government); 57, p.11 (UnitingCare).

25 See for example, *Submission* 89, p.4 (Nurses Board of WA).

26 *Committee Hansard* 28.4.05, p.22 (Mary Ogilvy Homes Society)

27 *Submission* 150, p.17 (VAHEC).

- any facility can be labelled dementia specific whether it is purpose designed for dementia or not. This makes choosing the correct facility very difficult for carers and service providers;
- organisations wishing to build dementia specific facilities are unable to easily access best practice guidelines for their design or functional management;
- the length of stay of older adults in the acute hospital setting increases because of lack of facilities and creates the repeated transfer of residents between non purpose built faculties and increases safety risks for the individual residents, other residents and staff; and
- purpose built faculties have no policy or funding incentives to be utilised for older people with the greatest need for that specialised environment. Therefore in practise they appear to be utilised for residents that solve facility management problems rather than the strategic needs of the older people with dementia.²⁸

5.28 The Mary Ogilvy Homes Society commented that while the Commonwealth has provided a funding component for dementia care, this is only recurrent funding: 'the majority of the industry would agree that it needs to be carried out in what is known as a segregated model, and that requires a capital funding stream to build buildings that are architecturally appropriate for residents with dementia'.²⁹

5.29 Witnesses also identified a number of other difficulties in meeting the needs of residents with dementia. These included:

- people with dementia and co-existing psychiatric illnesses or intellectual disability require additional support and specialised management which is not always available;
- a need for further education and training especially in managing challenging behaviours, however, training budgets which could adequately meet the needs of staff;
- people with dementia who are physically fit often have difficulty finding appropriate placement. Many facilities are not equipped to manage people who are stronger and more agile;
- residential facilities have great difficulty in accessing specialist advice for residents with dementia and very complex needs and residents are sent to emergency departments unnecessarily;
- the need for alternative placement options where facilities cannot manage people; and

28 *Submission 46*, pp.1-2 (Dr R McKay, Ms R McDonald).

29 *Committee Hansard 28.4.05*, p.22 (Mary Ogilvy Homes Society).

- lack of a thorough profile of people on admission, due either to the inappropriateness of the assessment tool or the desperation to place people.³⁰

5.30 The ANF Victoria Branch noted that the Ageing in Place initiative was intended to address the needs of aged care residents with dementia but it argued that it had not been successful in giving high care dementia residents access to appropriate nursing and health care. Low care facilities or hostels do not have access to adequate nursing care as these facilities are only required to employ registered nurses on a 'casual' or 'call in basis'. The ANF argued that care in such facilities is not always and concluded that 'such lack of access to skilled nursing care by high care residents is untenable'.³¹

Mental health support

There are special needs associated with people with mental illness or psychiatric disability, and a body of provocative literature has emerged over the last couple of decades showing that mental illness is commonly undetected and often poorly managed in residential settings. Some actually put the figure as high as 90 per cent or more of those in nursing home care or aged care facilities fulfil criteria for one or more psychiatric disorders in an environment that often presents significant difficulties for assessment and treatment.³²

5.31 Many witnesses pointed to the need for specialised care for those elderly with mental health problems. Witnesses noted that more people who are ageing have a mental illness, particularly depression, and moving into aged care facilities. The Mental Health Co-ordinating Council (MHCC) indicated to the Committee that its research had found that the ageing process tended to exacerbate the symptoms of mental illness. This was due to the experience of multiple losses and increased physical problems associated with ageing. Many older people with long standing mental illness also experienced isolation and illness as they had become estranged from family and friends and withdrawn from society.³³

5.32 UnitingCare indicated that as a result of people with mental illness accessing the aged care system there was an increasing need for crisis, acute and specialist psychiatric care. While Baptistcare stated that the needs of the mentally ill are very different to people who have dementia.³⁴

30 *Submission* 13, p.6 (Inner West 5 Home and Community Care Forum); see also *Submissions* 38, p.1 (Ms I Stanley); 2, p.1 (Shoalhaven Community Options Program); 203, p.11 (NSW Aged Care Alliance).

31 *Submission* 66, p.3 (ANF (Victoria Branch)).

32 *Committee Hansard* 18.3.05, p.4 (Office of the Public Advocate Qld).

33 *Submission* 75, p.1 (MHCC).

34 *Committee Hansard* 23.2.05, p.31 (Baptistcare); *Submission* 74, p.11 (ANHECA).

5.33 Staff in residential aged care facilities find it difficult to care for those with severe mental illness. The Office of the Public Advocate Qld commented that 'many of the staff in aged care facilities are not knowledgeable about even normal ageing and are not really able to understand some of the psychological symptoms and behavioural problems experienced by residents and, because of that, seldom seek appropriate mental health intervention once a problem is recognised'.³⁵

5.34 MCHH concurred with the Public Advocate and identified an urgent need for increased training of staff in aged care facilities in both the care of people with mental illness and dementia:

The needs of these residents are not currently being met to an adequate degree. This can cause deterioration in mental state and cognitive functioning with consequential decline in safety and quality of life. Additionally, when residents with these conditions are not cared for in an optimum manner, the resulting disturbances impact negatively on staff and other residents. This increases distress for residents and staff and contributes to the ongoing staff shortage.³⁶

5.35 Dr R McKay also commented on the need for training:

Training is very definitely an issue. You see some facilities where it is done very well and others where it is not. In the community in general the level of training seems to be declining, not improving...Whereas 10 years ago you could access people in the community with training, now it is extremely hard. That exacerbates the problem. You actually can have people going in to provide respite who actually may make the situation worse rather than better. This is not across the board. I have to emphasise that there are still some very good community services as well. But the training makes a huge difference.³⁷

5.36 ANF Australia stated the key to providing appropriate care is the education of staff who work in the acute sector and in the residential sector and the community sector. Education for mental illness 'has been neglected a little because of the focus on dementia because of the large numbers that we are going to be looking at of people with dementia. It is a real problem'.³⁸

5.37 The need for additional services and funding was highlighted in evidence. The ANF Victoria Branch stated that additional funding (around \$50 per resident per day) for patients with mental illness is provided by the Victorian Government to ensure that appropriate care is provided. The ANF stated that elderly Victorians with mental illness were well served by access to public nursing homes but 'these homes would

35 *Committee Hansard* 18.3.05, p. (Office of the Public Advocate Qld).

36 *Submission* 75, p.2 (MHCC); see also *Submission* 196, p.8 (Aged Care Qld).

37 *Committee Hansard* 11.3.05, p.66 (Dr R McKay).

38 *Committee Hansard* 11.2.05, p.40 (ANF).

not be able to continue to provide Psychiatric nursing care if they were reliant on Federal funding'.³⁹

5.38 It was argued that the Commonwealth's failure to provide supplementary funding for mentally ill residents, undermined the provision of appropriate care. In addition there is also limited access to psycho-geriatric services or behavioural management support services.⁴⁰ For example, the NSW Aged Care Alliance noted that there was only one psychogeriatric unit in NSW.⁴¹ In Queensland the Office of the Public Advocate noted that there was a problem with the provision of non-acute residential aged care places in Queensland for people with a psychiatric disability: 'it lags behind most other states, as does acute aged geriatric area spending as well as mental health spending more broadly. The lack of specific psychogeriatric services has been cited by the Royal Australian and New Zealand College of Psychiatrists by their faculty of psychiatry of old age.'⁴²

5.39 Dr McKay also commented that the design of facilities for those with mental illness was important. With properly designed facilities for people who have mental illness or cognitive impairment the demands on staff are reduced, agitation is reduced and increases the safety for staff and residents.⁴³

Homeless people

The homeless elderly are certainly living in our community and they are doing it very tough. They deserve respect and they deserve to be treated with dignity. This is a critical time to ensure policy and funding decisions ensure homeless older people are not forgotten and indeed they, and those who care for them, should receive the assistance they need to ensure the highest quality of life.⁴⁴

5.40 The elderly homeless are a small group but who, as the Hogan Review observed, are one of the most difficult groups to place in residential care.⁴⁵ In relation to funding of their aged care, the Hogan Review noted that 'while the elderly homeless attract a concessional resident supplement, they generally have no ability to pay an accommodation bond, compounding the problem of access to mainstream services'. The Hogan Review commented that given the funding problems of providing care for the elderly homeless, there are very substantial grounds for providing for the special needs of the most deprived of the elderly homeless. The Review's recommendation included extension of the funding supplement to disadvantaged groups, including the

39 *Submission* 66, p.3 (ANF Victorian Branch).

40 *Submission* 196, p.8 (Aged Care Qld).

41 *Submission* 203, p.11 (NSW Aged Care Alliance).

42 *Committee Hansard* 18.3.05, p.4 (Office of the Public Advocate Qld).

43 *Committee Hansard* 11.3.05, p.66 (Dr R McKay).

44 *Committee Hansard* 11.2.05, p.4 (CHA).

45 Hogan Review, p.194.

elderly homeless, and targeted capital assistance to assist those services experiencing exceptional circumstances.⁴⁶

5.41 The Commonwealth's response to the Hogan Review did not include extension of the funding supplement to the homeless and noted that the care needs of people from diverse or disadvantaged backgrounds are supported by a number of Commonwealth programs.⁴⁷

5.42 As with evidence to the Hogan Review, witnesses pointed to the special needs of the elderly homeless and the difficulties they face accessing care. The elderly homeless are predominantly male and access services at a younger age than others. Generally homeless people or those at risk of homelessness have poor diets, have multiple health problems, multiple cognitive problems, are often alcohol dependent and are subject to social isolation.

5.43 The homeless lifestyle hastens the ageing process with premature ageing found in people in their 40s who have been homeless for a number of years. As a result they may require the intensive services appropriate to older people, such as HACC, CACP and residential aged care. The Brotherhood of St Laurence stated that they are often excluded from these services as they do not meet the age criterion and conventional models do not suit this group.⁴⁸

5.44 When residential aged care is required, homeless people often find it difficult, if not impossible, to access services. CHA stated that currently, all providers who cater for this group are religious and/or charitable organisations.⁴⁹ St Bartholomew's noted that the small number of service providers that are willing to care for this group appeared to be dwindling. Mainstream services 'actively discriminate against this client group' and are reluctant to accept the elderly homeless because of their challenging behaviours.⁵⁰ For example, many homeless people have learnt coping behaviours which are not suitable in a normal community setting and so extra resources are often required to assist and retrain these people in acceptable behaviours. Homeless people often have poor interpersonal skills and are suspicious of people they don't know, including service providers, and it takes a great deal of time, which is not funded, to build up a relationship of trust. Other areas where homeless people require a different and intensive level of support include personal care, leisure activities, overcoming alcohol and/or drug dependency and medical and

46 Hogan Review, pp.xviii, xxi, 196.

47 The Hon Julie Bishop, Minister for Ageing, *Investing in Australia's Aged Care: More Places, Better Care*, May 2004, p.22.

48 *Submission 52*, p.5 (BSL).

49 *Committee Hansard* 11.2.05, p.4 (CHA); 23.2.05 p.24 (St Bartholomew's House).

50 *Submission 54*, p.2 (St Bartholomew's House).

dental issues.⁵¹ In addition, without the appropriate resources, the wellbeing of other residents and the occupational health and safety of staff are at risk.

5.45 VAHEC stated that the RCS, even when maximised, does not reflect the level of care required by people who have been homeless and stated that 'the intensive care and one-on-one support required by these people cannot be provided by organisations within the current funding structure'.⁵² St Bartholomew's noted that the Commonwealth had not implemented the Hogan Review's recommendation in relation to residential care. Witnesses recommended that the Aged Care Act be amended to include homeless people as a special needs group so that they can become eligible for Commonwealth funded aged care services.⁵³ The Brotherhood of St Laurence stated:

I would not see it as an extra stream of funding. I think it is more about tapping into the funding but creating a special needs group within the Aged Care Act. I think Professor Hogan recommended that homeless people be taken into account with special needs funding. I think the Commonwealth's response was more or less that they saw that as a state government responsibility and that it was already being well catered for. We would strongly argue that it is not being catered for at all and that there is a need for a funding stream for homeless people.⁵⁴

Ageing with disabilities

We know there are lots of adults with a disability who are now into their 50s and 60s, and parents who are in their 80s who have been caring for their loved one for over, in some cases, five decades. This is a very big cohort and I think that good collaboration between the states and the Commonwealth will be critical in terms of determining how this current unmet need will be addressed.⁵⁵

5.46 NCOSS noted that at present 11 per cent (30 200) of those aged 45-64 and 4 per cent (13 000) of those aged 65 or over with severe or profound core activity restrictions report an early onset disability (i.e. acquired before age 18). It is anticipated that there will be an increasing number of people with an early onset or longstanding disability who are ageing. Between 2000 and 2006, the total number of people with a severe or profound core activity restriction is expected to increase by 11.6 per cent (137 600 people).⁵⁶

51 *Submissions* 54, p.3 (St Bartholomew's House); 150, p.16 (VAHEC).

52 *Submission* 150, p.16 (VAHEC); see also *Committee Hansard* 11.2.05, pp.4, 12 (CHA); *Submission* 200, p.7 (Tasmanian Government).

53 *Committee Hansard* 23.2.05, p.24 (St Bartholomew's House).

54 *Committee Hansard* 27.4.05, p.14 (BSL).

55 *Committee Hansard* 18.3.05, pp.4-5 (Office of the Public Advocate Qld).

56 *Submission* 204, p.12 (NCOSS).

5.47 Witnesses argued that people ageing with disabilities requires specific and considered responses from all levels of government to meet their needs. ACROD focussed on the need for improved linkages between service systems:

Our view is that the response from governments to this development, this growing interface between ageing and disability, has been inadequate. Much of the policy effort at government level, it seems to me, in these human service areas where demand exceeds supply of services, goes into restricting entry, erecting barriers – setting restrictive eligibility criteria – rather than focusing on improving pathways and improving linkages between sectors. The result is an ineffective and inefficient interface between the two service systems.⁵⁷

5.48 For example, it was stated that ACAT teams make assessments where they are largely unaware of the supports and services offered by the disability sector.⁵⁸ A further example was that of the provision of aids and equipment. ACROD noted that the responsibilities for the provision of aids and equipment are divided across government departments and between the Commonwealth and the States:

...with the Continence Aids Assistance Scheme, the federal Department of Health and Ageing provides that for people in a rationed way; provides that for people who are under 65 or over 65 if they continue to work for eight hours a week or more, but when a person turns 65 and they have continence issues...They then become ineligible for that scheme and they have to then find an equivalent scheme funded by their state government.

That creates uncertainty and anxiety for them and I think is an inefficient and ineffective way of doing it. There has been enough research now that shows that, as a whole, the current schemes leave significant gaps, are inefficient and are fragmented.⁵⁹

ACROD proposed that the states, Commonwealth and relevant non-government organisations could come together and develop a coordinated or centralised system which could ensure that there was equitable and available aids and equipment for people which, in the long term, would allow people to remain independent and so reduce the pressure on more formal services.⁶⁰

5.49 In addition, it was argued that not only is funding not keeping pace with the increased demand for service, but also 'the funding formulae and administrative arrangements that govern the aged care and disability service systems seem to assume that a person is either disabled or aged, but cannot be both'. Like other witnesses, ACROD recommended that a person with a disability who is ageing should have

57 *Committee Hansard* 11.2.05, pp.49-50 (ACROD).

58 *Committee Hansard* 11.2.05, p.54 (ACROD).

59 *Committee Hansard* 11.2.05, p.56 (ACROD).

60 *Committee Hansard* 11.2.05, p.56 (ACROD).

simultaneous access to both aged care and disability service systems and funding streams, according to their need. However, ACROD noted:

...people who may have been long-term residents in state funded group homes – they may be people with an intellectual disability – and that is their home and has been their home for many years. When they age, because they are in a state administered and state funded group home, they are denied access to services that other people have access to; services such as community nursing, palliative care, dementia support and so on. This effectively denies them the right to age in place, which is a right that is increasingly expected by the general community.⁶¹

5.50 Baptistcare provided information on problems with service provision to a group of aged residents (some in their seventies) with disabilities in a residential facility in Perth. As it had to relocate the group from a facility which could no longer provide for their needs, it sought Community Aged Care Packages as a possible solution:

We saw this as a possible solution that we might be able to work towards as we endeavour to relocate these people. We made an approach to the state government here, with whom we are working, and they in turn made an approach to the Commonwealth office here. We were not at the meeting, but the response that we were given was that there appears to be little scope in the Aged Care Act for the two bodies to work together to come up with a solution that may see something like that being a new initiative within an existing program. So that is an example we had towards the end of last year which I put to Minister Bishop as an opportunity that maybe her department could have a look at.⁶²

Baptistcare concluded that 'there is an opportunity for Community Aged Care Packages to go out to people who are currently living either in the community or, perhaps, in a facility such as the one we have. That would address their immediate needs and let them remain where they are rather than relocate them'.⁶³

5.51 The Greenacres Association commented that there were concerns about ageing people with a disability who have been living in the community and working in business enterprise. Greenacres stated that:

- there is an inability to secure the appropriate supports and services that they require to remain living a meaningful live in the community as they age;
- there is a lack of, and uncertainty about, service provision makes it difficult, if not impossible for these people and their supports to plan for the future; and

61 *Committee Hansard* 11.2.05, p.50 (ACROD).

62 *Committee Hansard* 23.2.05, pp.33-34 (Baptistcare).

63 *Committee Hansard* 23.2.05, p.34 (Baptistcare).

- services for ageing people with a disability must be sufficiently flexible to meet their diverse needs and must take account of changes in those needs as they further age.

5.52 The Greenacres Association noted that the people with disability they cared for had been supported for most, if not all their lives and 'would not cope without support (at least initially) in generic services, and the generic service participants were not keen to integrate with people with a disability'. Therefore effective transition programs and services are essential as a person with a disability reaches the age of retirement and eligibility for aged care services.⁶⁴ ACROD stated that transition from employment to retirement needed to be gradual so that the person had time to adapt to change. Initially the supported employee should receive a mix of non-employment activities and employment. ACROD stated that this requires movement from Commonwealth funded services to appropriate day activities funded by the States or Territories and aged care services funded by the Commonwealth: 'in theory bureaucratic and jurisdictional boundaries should not impede this, but, in practice, the boundaries are often barriers'.⁶⁵

5.53 The Greenacres Association also stated that the Commonwealth's 'Assistance for Business Services' provides for access to a personal case manager to support those retiring from a business service. However, Greenacres commented that:

In theory this sounds fantastic, but the reality is that there are not services out there for these people to access. In the Wollongong area alone there was not a single appropriate service available until the NSW Department of Ageing Disability and Home Care funded the Retirement Options Program.⁶⁶

5.54 Greenacres provided the Committee with details of its ageing service, Greenacres Retirement Options (GRO). This service provides a centre based day program for eligible individuals. The service offers a variety of activities both at the centre and in the community. Assistance for each activity is provided, the average being one GRO staff member to five retirees (or less). Priority is given to those individuals over the age of 55 that are retiring from a business service or have already retired and living with a family member. Retirees that live with a parent carer have the highest priority. Greenacres commented that this type of services is ground-breaking and the first of its kind in Australia.

5.55 The Department of Family and Community Affairs (FaCS) stated that the issue of people ageing with disabilities was a concern:

64 *Submission 32*, p.4 (Greenacres Association) see also *Committee Hansard* 11.2.05 p.50 (ACROD).

65 *Submission 26*, p.3 (ACROD).

66 *Submission 32*, p.6 (Greenacres Association).

Certainly the issue of people with lifelong disabilities who are ageing is a growing concern to us. It is in some ways a relatively new phenomenon. We are not accustomed to having large numbers of people with disabilities live to such an age, where they would be regarded in the traditional sense as potential aged care clients.⁶⁷

The Department went on to note that 20 years ago there were only a handful of older people with down syndrome. Now there are over 1 000 people in Australia who are aged with down syndrome. The Department commented:

We are clearly starting to face very real issues at that older age nexus. I admit that it is not something in the disability world that a great deal of attention has been paid to in the past. Increasingly we are doing that but I would still come back to my earlier point that it is really a case of the appropriate expertise and appropriate kinds of support, rather than trying to look at how a mix of services might go into the one service. I am happy to accept that there are needs for improvement in the services.⁶⁸

5.56 The Department of Health and Ageing commented that it and FaCS 'have been working on, including through a small number of pilots under the aged care innovative pool, to test that issue of the increasing ageing needs being overlaid on disability needs'.⁶⁹ The Innovative Pool offered flexible aged care places to the States and Territories and other aged care providers, for time limited pilots to trial new models of service delivery at the disability services/aged care interface. Two specific categories for people with a disability were targeted, the first being for people with disabilities who are ageing. Six projects have been approved in this category for 2002-03 and a further three for 2003-04. These projects are all providing additional aged care services for people with disabilities who are ageing in disability supported accommodation settings.⁷⁰

5.57 ACROD supported this development and stated:

That is very good and I know that those pilots are subject to evaluation this year. I would hope that, subject to that evaluation, they not only continue but that the principle of combined funding and joint funding that is established by those pilots can be more broadly applied...It is a very promising development, because it involves cooperation between Commonwealth and state and sensibly involves shared funding. The clientele that are being provided with the service in those pilots have mixed needs and some of those needs derive from life-long disability and others derive from the fact that they are growing old. It makes sense, from a policy point of view, for both levels of government to be involved.⁷¹

67 *Committee Hansard* 11.2.05, p.83 (FaCS).

68 *Committee Hansard* 11.2.05, p.84 (FaCS).

69 *Committee Hansard* 11.2.05, p.83 (DoHA).

70 *Submission* 191, p.37 (DoHA).

71 *Committee Hansard* 11.2.05, p.50 (ACROD).

5.58 In regard to the provision of age related services to those ageing in supported accommodation, FaCS stated that it is government policy that Community Aged Care Packages are not available to people in subsidised residential care and that:

The disability residential care services or the accommodation support services are very similar in principle at least to many other residential services. We would expect that the organisations running those services will be meeting the needs of the people that they are providing services for. It is difficult for me to think through why there would be a need for, or an expectation that – say for our colleagues in the Department of Health and Ageing but in health and aged care services generally – aged care services of any kind would be provided to somebody who is already in a residential care service and presumably having their residential care needs met.⁷²

FaCS further commented that it was discussing the growing number of issues around people with disabilities living in residential care services who are developing conditions traditionally associated with ageing, such as Alzheimer's dementia, where there is again a growing recognition that those services do not necessarily have the expertise and the experience in handling those:

As part of our current round of Commonwealth-state arrangements there are a couple of parts within that where we have agreed with the state governments that there are areas of expertise which are needed and that is something that we are discussing with our colleagues in Health and Ageing.

I think it is going a bit far in that environment to suggest that there is a service model which should be provided. We certainly recognise there are areas where greater expertise is needed and state governments are working increasingly with Health and Ageing officers in the states to do that, but I do not think there is a situation at this stage where it is appropriate for two models of service or two accommodation support services to be provided to a person in the one residential setting. I agree with the need but I am not convinced there is a need for services from two agencies to go to that one person.⁷³

Conclusion

5.59 The discussion in this chapter briefly canvasses a number of significant issues. Solutions to these issues must be found to ensure that adequate aged care is provided to all those in aged care facilities. The Committee considers that if the Commonwealth takes on the care of those in aged care, the Commonwealth is responsible for the total care of that person and the provision of all services. It must ensure that all matters pertaining to a person accommodated in an aged care facility are taken into account and the appropriate services are provided whether they arise from a condition related to ageing or a pre-existing condition such as a mental health problem or they arise from lifestyle such as homelessness.

72 *Committee Hansard* 11.2.05, p.82 (FaCS).

73 *Committee Hansard* 11.3.05, pp.82-83 (FaCS).

5.60 In relation to the supplementary funding for dementia, while this is a welcome initiative, the Committee considers that it is not appropriate that these funds are drawn away from other programs. The costs of dementia and palliative care needs are increasing as are all costs in residential aged care. Funding the supplement should be provided in addition to that already provided. The Committee also considers that an appropriate review of the additional costs of providing care for those with dementia and those needing palliative care should be undertaken to ensure the funding supplement is sufficient to provide adequate care.

5.61 The Committee also notes that dementia is now a Commonwealth National Health Priority and that Australian Health Ministers have jointly agreed to the development of a National Framework for Action on Dementia. The Committee considers that this is a significant opportunity for ensuring that the increasing numbers of older Australians who are suffering from dementia receive adequate care and that they and their families are able to access a range of accommodation and care options.

Recommendation 29

5.62 That the supplementary funding for aged care for residents with dementia be provided for by additional funding and not funding from within the current budget.

Recommendation 30

5.63 The Committee recognises that the Australian Health Ministers have jointly agreed to the development of a National Framework for Action on Dementia and that the Commonwealth has recognised dementia's significance with a \$320.6 million package of support over five years. The Committee recommends that all jurisdictions work together with providers and consumers to expedite the finalisation and implementation of the Framework to assist all dementia sufferers.

Recommendation 31

5.64 That the Commonwealth undertake a review of the additional costs of providing care for those with dementia and those needing palliative care to ensure that the new funding supplement will be sufficient to provide adequate care.

5.65 Mental illness is a major health concern in the community. Evidence points to the exacerbation of mental illness with ageing. The elderly with mental health illness or psychiatric disability require additional and specialised care. They must have access to adequate accommodation and support options. In order for this to occur, the Committee considers that the funding supplement should be extended to services providing care for older people with mental illness. In addition, the Committee considers that a review of the provision of psychogeriatric services and the effectiveness of psychogeriatric care units needs to be undertaken.

5.66 The Committee also considers that there is a need to increase the training of the aged care workforce to ensure that mental illness in the elderly is recognised and that there is a skilled workforce to meet the needs of elderly people with mental illness.

Recommendation 32

5.67 That the Commonwealth establish a funding supplement for residents in residential aged care who have additional needs arising from mental illness.

Recommendation 33

5.68 That the Commonwealth investigate the provision of psychogeriatric services and the effectiveness of psychogeriatric care units.

Recommendation 34

5.69 That the Commonwealth provide targeted funding for the education of the aged care workforce caring for people with mental illness.

5.70 The Committee considers that while the elderly homeless are a small group, they require additional services to ensure that they receive appropriate aged care. The Committee is therefore disappointed that the Commonwealth has not provided a funding supplement for the elderly homeless. The Committee considers that the Commonwealth should reconsider this decision.

Recommendation 35

5.71 That the Commonwealth establish a funding supplement for residents in residential aged care who have additional needs arising from homelessness.

5.72 The number of people ageing with a disability is growing and they will need to access quality aged care services. While it is acknowledged that the Commonwealth is aware of this problem, the Committee is concerned that the barriers between the jurisdictions and within jurisdictions may impede the development and provision of services for those ageing with a disability.

5.73 Those working in the disability sector have built up the skills and resource base to assist those with disabilities. To these must now be added the skills and resources of the aged care sector. Without an understanding of both disability and ageing those ageing with a disability will not receive an optimum level of care.

5.74 The Committee considers a specific and focussed response is required.

Recommendation 36

5.75 That the Commonwealth respond to the growing needs of people ageing with disabilities by consulting with the States and Territories and stakeholders to identify ways to improve access by people ageing with a disability to appropriate aged care services including service provision in supported accommodation.

CHAPTER 6

COMMUNITY CARE PROGRAMS

...significant reform is needed to Australia's community care system if it is to meet the expectation placed on it of assuming an increasingly significant role in the future of our care system and if it is to continue to provide high quality care services to older people.¹

6.1 This chapter discusses the adequacy of community care programs in meeting the current and projected needs of the elderly. Community care programs are aimed at enabling frail older people and people with a disability to remain in their own homes for as long as possible. The flexibility of community care means that a well funded program can deliver a service that is tailored to individual needs and provides continuity of care as recipients' needs change.

6.2 The provision of high quality community care that helps people live in their own homes longer has several advantages:

- most people prefer to live in their own home rather than moving to a residential care facility;
- community care helps people retain their independence for longer;
- it is the sign of a healthy society to have more assistance provided to people living in the general community for as long as possible; and
- provision of high quality community care uses less health and aged care resources as it avoids costly admission to residential aged care and acute care.²

6.3 The demand for community care programs is expected to increase over coming decades. The Department of Health and Ageing (DoHA) estimated that based on current service use patterns, the number of people over 85 years who rely on community care programs will rise from 81 000 people in 2002 to 140 000 people in 2019. It is estimated that the number of people across all age groups who rely on community care programs will increase from approximately 650 000 people per annum in 2002 to approximately 970 000 people in the year 2019.³

Community care services

6.4 A number of community care programs provide a range of services including the Home and Community Care (HACC) Program, Community Aged Care Packages

1 *Submission 173*, p.7 (ACSA).

2 *Submissions 166*, p.12 (CHA); 74, p.13 (ANHECA).

3 DoHA, *A New Strategy for Community Care: Consultation Paper*, March 2003, p.8.

(CACPs), the Extended Aged Care at Home (EACH) program and Veterans' Home Care (VHC). Other services include respite care, including the National Respite for Carers Program (NRCP) and support for carers. Of the total number of Australians aged 70 and over, 15.1 percent use HACC services, 7.8 percent are in residential care and 1.5 percent receive CACPs.⁴

6.5 The main differences between HACC, CACPs and EACH programs are summarised in table 6.1.

Table 6.1: Features of HACC, CACPs and EACH programs

	HACC	CACPs	EACH
<i>Range of services</i>	Wider range of services available	Narrower range of services available	Narrower range of services available
<i>Relationship to residential care</i>	Aims to prevent premature or inappropriate admission	Substitutes for a low care residential place	Substitutes for a high care residential place
<i>Eligibility</i>	ACAT assessment not mandatory	ACAT assessment mandatory	ACAT assessment mandatory
<i>Funding</i>	Cost shared by the Commonwealth, State and Territory governments and client contributions	Funded by the Commonwealth Government and client contributions	Funded by the Commonwealth Government and client contributions
<i>Target client groups</i>	Available to people with a greater range of care needs	Targets people with care needs similar to low level residential care	Targets people with care needs similar to high level residential care
<i>Size of program</i>	\$1.2 billion funding in 2003-04 Approximately 707 207 clients in 2003-04	\$307.9 million funding in 2003-04 28 921 operational places in 2003-04	\$15.5 million funding in 2003-04 858 operational places at 30 June 2004

Source: Productivity Commission, *Report on Government Services 2005*, Vol.2, p.12.18.

6.6 The HACC program, which provides the main community care program, is described in some detail below. CACPs provide an alternative home-based service for older people who Aged Care Assessment Teams (ACATs) assess as eligible for care equivalent to low level residential care. EACH provides a community alternative to high level residential aged care services. The program provides individually planned and coordinated packages of care designed to meet older people's daily care needs in

4 *Submission 191*, p.42 (DoHA).

the community. The EACH program differs from the CACP program in that it targets frail older people who would otherwise be eligible for high level residential aged care. An EACH package typically provides 15-20 hours of direct assistance each week. The services of the VHC program target veterans and war widows/widowers with low care needs. The program provides home support services, including domestic assistance, personal care, home and garden maintenance, and respite care. Other services, such as community transport and delivered meals are also available under Department of Veterans' Affairs arrangements with State governments.

Home and Community Care Program

6.7 The Home and Community Care (HACC) Program provides a range of services including:

- domestic assistance – help with cleaning, cooking, washing and ironing;
- personal care – bathing and dressing;
- food services – meals on wheels, centre based meals, help with shopping;
- community respite – to give carers a break or for frail older people living alone;
- transport – practical assistance with individual transport needs;
- home maintenance or modification – assistance to maintain a person's home, garden or yard to keep it safe; and
- home/community nursing – provided by trained nurses on a regular or one-off basis, in home or from a community centre.

Aids and appliances is one of the 'excluded services' for HACC funding because funding is already provided for these services through other government programs.

6.8 HACC is a jointly funded program. States and Territories are required to match the Australian Government annual offer of funding. The previous year's HACC funding for a State/Territory forms the basis of the next year's funding plus whatever growth is provided for in the Commonwealth Government Budget. The annual growth component has been set at cost indexation plus a real growth of 6 per cent for some years now.

6.9 The Commonwealth Government contributes approximately 60 per cent of Program funding and maintains a broad strategic policy role while State and Territory Governments funded the remainder. State and Territory Governments are responsible for the day-to-day management of the HACC Program. Total national expenditure on HACC was of \$1.2 billion in 2003-04 consisting of \$732.4 million from the Commonwealth Government and \$471.3 million from State and Territory Governments.⁵

5 Productivity Commission, *Report on Government Services 2005*, Vol. 2, p.12.11.

6.10 Table 6.2 provides details of total Commonwealth and States' HACC expenditures from 1995-96 to 2003-04.

Table 6.2: Expenditure on the HACC Program, 1995-96 to 2003-04

	NSW	VIC	QLD	SA	WA	TAS	NT	ACT	C'wealth
	\$m	\$m	\$m	\$m	\$m	\$m	\$m	\$m	\$m
1995-96	139.450	118.829	65.708	37.923	43.123	11.794	2.449	3.966	423.242
1996-97	143.780	126.635	73.506	41.734	45.687	12.720	2.691	4.467	451.220
1997-98	150.187	133.990	80.476	43.394	47.456	13.047	2.885	4.894	476.329
1998-99	155.862	141.226	87.705	44.751	48.960	13.322	3.070	5.304	500.200
1999-00	161.760	148.900	95.620	46.170	50.530	13.565	3.270	5.750	525.565
2000-01	174.129	157.230	104.765	50.047	54.587	14.630	3.642	6.424	565.454
2001-02	190.262	167.331	116.991	54.023	60.007	15.860	4.069	7.039	615.582
2002-03	209.522	178.703	131.375	58.556	66.289	17.303	4.559	7.779	674.086
2003-04	228.726	189.879	145.883	63.086	72.497	18.743	5.058	8.516	732.388

Source: Submission 191, p.43 (DoHA).

6.11 The number of clients accessing HACC services has increased from 375 000 in 1995-96 to 700 000 in 2002-03 – however this only represents 40 per cent of the HACC target population.⁶ Client numbers increased to 707 200 in 2003-04. The HACC target population comprises people with moderate, severe and profound disabilities, as defined by the ABS Survey of Disability, Ageing and Carers. Identified special needs groups within the HACC target population include: people from culturally and linguistically diverse backgrounds, Indigenous Australians, people with dementia, financially disadvantaged people, and people living in remote or isolated areas. Carers of people in the HACC target group can also receive support through the HACC Program's respite care and counselling services.

6.12 Community and voluntary organisations, religious and charitable organisations, commercial organisations in some States, as well as State and Territory Government agencies and Local Government may provide HACC services.

Funding

6.13 Concerns were expressed at the adequacy of funding levels to meet the current and future demand for HACC services.⁷ Submissions noted that demand for HACC services is likely to increase significantly in the medium to longer term as a result of:

- increasing numbers of older people due the ageing of the population and increased life expectancy;

⁶ *Submission* 191, p.50 (DoHA).

⁷ *Submissions* 166, p.12 (CHA); 173, pp.7-8 (ACSA); 174, p.14 (COTA National Seniors).

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- increasing rates of 'core activity restriction' among older people as a result of people living longer with more long-term health conditions and frailties; and
 - increasing preferences for community based services over residential care services as older people seek to remain in their own homes for as long as possible, resulting in demand for high level community care services.⁸

6.14 DoHA projections of the HACC target group, comprising people with moderate, severe and profound disabilities, over coming years based on ABS population projections indicate the numbers of persons involved will increase by about 2 per cent per year which is about twice the rate of the general population. The HACC client base continues to increase as the number of persons aged 70 and over increases relative to the general Australian population. DoHA stated that the current 6 per cent annual real growth in funding for HACC is considerably higher than the current projection that the HACC target population will increase by around 2 per cent per annum.⁹

6.15 Commonwealth Government funding for HACC has continued to increase. Over the nine years from 1995-96 to 2004-05, the Commonwealth has increased the funding available for HACC services by 87 per cent, or approximately \$369 million. Total Commonwealth and State Governments HACC funding in 2003-04 was \$1.2 billion.¹⁰

6.16 In relation to unmet need for HACC services, DoHA noted that the ABS Survey of Disability, Ageing and Carers 1998 identified a group of some 4 per cent of those people with a moderate, severe or profound disability (the definition of the HACC target population) who were in need of services but were not currently receiving any services. A further 32 per cent of this HACC target group indicated that though they were in receipt of services, they would like more services. These survey results have been taken as a broad measure of the unmet demand for community care services.¹¹

6.17 DoHA noted that:

...additional upwards pressure on demand for services is expected to continue. The ongoing increase in demand will result from the relative increase in the number of people who are 70 years of age and over, an increase in the care needs of the increasing number of older aged persons, and the continuing decline in the availability of informal care.¹²

8 *Submissions* 202, p.18 (DADHC & NSW Health); 150, pp.19-20 (VAHEC).

9 *Submission* 191, pp.44,50 (DoHA).

10 *Submission* 191, p.45 (DoHA).

11 *Submission* 191, p.46 (DoHA).

12 *Submission* 191, p.47 (DoHA).

6.18 A number of groups argued that HACC funding needs to be increased by an initial 20 per cent and at least 6 per cent per annum (plus indexation) each year to ensure that a more appropriate level of care can be provided to existing clients and to ensure sufficient growth in funding to match future growth in demand.¹³ Carers Australia argued that funding for HACC services should be increased by at least 30 per cent to meet unmet demand.¹⁴

6.19 Submissions also argued that the indexation method for the HACC programs, through the Commonwealth Own Purpose Outlays (COPO), is inadequate and fails to keep pace with the rising costs of providing community care.¹⁵ Aged and Community Services Australia (ACSA) suggested that, in the longer term, community care providers should be funded to a level which supports the actual costs of providing care. This could be best be achieved by linking community care funding to an appropriate index of health sector wages.¹⁶

Recommendation 37

6.20 That, while welcoming the increases in Commonwealth and State and Territory funding for the Home and Community Care Program over recent years, the Commonwealth and State and Territory Governments increase funding for HACC services to ensure more comprehensive levels of care can be provided to existing clients and to ensure sufficient growth in funding to match growth in demand.

Recommendation 38

6.21 That the Commonwealth review the indexation arrangements for the Home and Community Care Program to reflect the real costs of providing care.

Special needs groups

6.22 Evidence indicated that within the HACC target population there are several groups that find it more difficult to access services. These groups include:

- people from culturally and linguistically diverse (CALD) backgrounds;
- Aboriginal and Torres Strait Islander people;
- people with dementia;
- financially disadvantaged people; and
- people living in remote and isolated areas.

13 *Submissions* 170, p.17 (ACS of NSW & ACT); 125, p.10 (ACS SA& NT); 203, p.16 (NSW Aged Care Alliance); 209, p.2 (Community Care Coalition).

14 *Submission* 111, p.10 (Carers Australia).

15 *Submissions* 173, p.7 (ACSA); 170, p.17 (ACS of NSW & ACT); 111, p.10 (Carers Australia).

16 *Submission* 173, p.8 (ACSA). See also *Submission* 101, p.8 (MAV).

People from culturally and linguistically diverse backgrounds

6.23 Submissions noted that people from CALD backgrounds are relatively underrepresented in using core HACC services such as home care, delivered meals and personal care compared with people whose first language is English. Data indicate that approximately 25 per cent of HACC clients are people whose birthplace is outside Australia, with 9.2 per cent speaking a language other than English at home.¹⁷ It was argued that it is essential that people from CALD communities have fair and equitable access to HACC services.

6.24 Groups representing CALD communities argued that there needs to be:

- increased flexibility in the design of HACC services to meet the particular needs of CALD communities;
- increased funding to support ethno-specific delivery of HACC services, especially social support programs;
- increased support and funding for the HACC in-home respite care program, the value of which is underated for CALD communities;
- the development of a uniform national framework to deliver culturally competent care;
- the creation of planning and funding allocation benchmarks and targets to improve CALD communities' access to services;
- cultural competence training across the HACC sector and evaluation of programs in relation to their cultural appropriateness; and
- improved data collection and reporting.¹⁸

6.25 Submissions also argued that CALD ageing communities require specialised intervention strategies such as the availability of bi-lingual assessment and care workers and extensive information initiatives to better inform particular communities of the availability of HACC services.

Aboriginal and Torres Strait Islander people

6.26 Submissions noted that there is a need to improve the accessibility and appropriateness of community care services for Aboriginal people. Some 2.4 per cent of all HACC clients are from an Indigenous background. It was noted that the low utilisation of residential aged care by Aboriginal people places an increased emphasis on the provision of culturally-appropriate community-based supports. It was also argued that funding for community care services needs to take account of the fact that

17 HACC Program Minimum Data Set, 2003-2004 Annual Bulletin, DoHA, November 2004, pp.6,20.

18 *Submissions* 178, pp.17-20 (ECC of NSW); 82, p.3 (ECC of Victoria); 43, pp.2-4 (ECCFCSC). See also *Submission* 203, p.17 (NSW Aged Care Alliance); *Committee Hansard* 27.4.05, pp.38-41 (ECC of Victoria).

Indigenous people have a much poorer health status and die at a younger age than the general population.¹⁹

6.27 Submissions argued that there is a need to provide Aboriginal-specific services delivered by appropriately trained Aboriginal people – such services are at present inadequate and ad hoc. Submissions also noted the need to provide training to ensure that culturally appropriate staff are employed by mainstream services to ensure services cater for the particular needs of Aboriginal people.²⁰

People with dementia

6.28 Submissions noted that with the ageing of the population, the number of people living with dementia will increase significantly. This increase in numbers will represent a significant driver in the growing demand for additional community care services. While some people with dementia will need support from specialist services, the bulk of the support will need to come from mainstream community care services.²¹

Homeless people

6.29 Submissions argued that many homeless people or people at risk of homelessness suffer from premature ageing and require the intensive care services appropriate to older people, such as HACC or CACP services, but they are often excluded from these services because they do not meet the age criterion. The Brotherhood of St Laurence (BSL) suggested that the HACC guidelines need to be amended so that homeless people are recognised as a special needs group so that these people would be eligible for HACC services due to premature ageing.²²

People living in remote areas

6.30 Submissions noted that HACC services are more limited in many rural and remote areas. The distribution of HACC clients among remote and very remote areas is 1.6 per cent and 0.7 per cent respectively. While many people in these areas are eligible for HACC and other community care programs there are often long waiting lists. For those receiving services there is often difficulty moving through the various levels of care as their needs change. In rural and remote areas, with relatively more limited access to residential aged care, it is important to ensure people can access community care services.²³

19 *Submission* 173, Attachment 2 (ACSA).

20 *Submissions* 204, pp.18-20 (NCOSS); 203, p.17 (NSW Aged Care Alliance).

21 *Submission* 173, Attachment 2 (ACSA); 158, p.4 (Advocacy Tasmania).

22 *Submission* 52, p.5 (BSL). See also *Committee Hansard* 23.2.05, pp.28-29 (St Bartholomew's House).

23 *Submissions* 208, pp.8-9 (NRHA);165, pp.2-3 (TasCOSS).

6.31 Submissions noted that HACC providers in rural and remote areas are disadvantaged financially in operating services. For residential care providers a supplement to assist with viability is applied according to the geographical remoteness of the service. Extra costs associated with travel and operational costs are not taken into consideration in subsidy levels for HACC services. Aged Care Qld argued that the Commonwealth should extend the viability supplementation to the community care programs that it funds.²⁴

Conclusion

6.32 Evidence indicates that additional resources need to be provided to special needs groups within the HACC target population to ensure equitable access to HACC services. The Committee also believes that the particular needs of homeless people need to be more adequately recognised under the HACC program. The Committee also considers that a funding supplement should be available for community care services operating in regional and rural areas.

Recommendation 39

6.33 That the Commonwealth and States and Territories substantially increase funding for identified special needs groups within the HACC target population including people from culturally and linguistically diverse backgrounds; Aboriginal and Torres Strait Islander people; people with dementia; financially disadvantaged people; and people living in remote or isolated areas.

Recommendation 40

6.34 That the HACC guidelines be amended to recognise homeless people or people at risk of homelessness as a special needs group.

Recommendation 41

6.35 That the Commonwealth introduce a funding supplement to reflect the additional costs of providing community care services in regional, rural and remote areas.

Other community care programs

Community Aged Care Packages

6.36 As noted above, the CACP program is a community alternative for older people with complex care needs who wish to remain living in their own homes with care and community support. The program provides individually tailored packages of care services that are planned and managed by an approved provider. The services

24 *Submission 196*, p.11 (Aged Care Qld).

provided as a part of a CACP are designed to meet people's daily care needs and may vary as an individual's care needs change.

6.37 The funding for the CACP program for 2004-05 is \$327.4 million, with an additional \$2.4 million for CACP Establishment Grants. A further 6635 Community Aged Care Places will be made available through Approvals Round over the next three years, including 2020 through the 2004 Aged Care Approvals Round.²⁵ DoHA stated that the CACP program will continue to receive increased funding to ensure the future needs of the elderly in the community are met.²⁶

Extended Aged Care at Home

6.38 As discussed above, the Extended Aged Care at Home (EACH) program aims to provide an alternative to high level residential care for frail older people living in their homes, with the objective of improving the quality of life for the frail older people and reducing inappropriate access to both acute and residential care settings.

6.39 EACH packages are individually tailored, coordinated and planned packages of care, targeted at the frail aged whose care needs are assessed as equivalent to those who require high level residential care, but have expressed a preference to live at home.

6.40 The initial number of packages during the pilot stage was 290 packages. In the 2002 Aged Care Approvals Round (ACAR), a further 160 EACH packages were made available to provide for a moderate expansion of the EACH Program. This expansion aimed to build provider familiarity with the program and provide an Australian-wide base for program development. In the 2003 ACAR, an additional 474 new places were made available bringing the total places to 924.

6.41 EACH packages are currently funded at an average of \$107 per day, which is equivalent to the Resident Classification Scale level 2 of high residential care. This is an average of \$39 055 per annum per package. Expenditure for the EACH program in 2004-05 is estimated to be some \$40 million.

6.42 DoHA stated that the EACH program continues to receive increased funding to ensure the future needs of the elderly in the community are met. To support continued strong growth in community care, 900 additional EACH places will be made available in 2004-05. In 2004-05 the number of EACH places will increase to 1824 places.²⁷

25 *Submission* 191, pp.50-51 (DoHA).

26 *Submission* 191, p.51 (DoHA).

27 *Submission* 191, pp.51-52 (DoHA).

Views on programs

6.43 Generally, the evidence indicated that these community care programs provide valuable services but need further resources so that more services can be provided. The Committee received only limited evidence commenting on specific programs. One submission noted that while EACH is a laudable program the differences in level of care available under CACP funding and EACH packages creates problems in maintaining clients in their own homes because of the very different levels of care able to be provided under the different programs.²⁸ Another submission noted that CACPs and EACH packages are now seen as a way for HACC providers to 'offload' high user clients that in the past managed well with HACC supports.²⁹

6.44 A recent House of Representatives report into ageing noted the growing demand for EACH places and the need for further resources to increase the number of these packages to enable people to have the chance of receiving high care at home.³⁰

6.45 Many submissions argued that funding for these community care programs should be increased by 10 per cent to address past underfunding of these programs.³¹

6.46 In the 2004-05 Budget the Government changed the aged care planning ratio to increase the number of CACPs from 10 per 1000 over the age of 70 years to 20 per 1000 people over the age of 70. Submissions generally welcomed these changes.³²

Recommendation 42

6.47 That, while welcoming the increases in Commonwealth funding for Community Aged Care Packages and Extended Aged Care at Home packages over recent years, the Commonwealth increase funding for these programs to meet demand for these programs and to provide viable alternatives to residential aged care.

Adequacy of community care programs

6.48 While there is widespread acknowledgement of the significant contribution community care programs make in enabling older people remain in their own homes, evidence indicated concerns about the adequacy of some aspects of current arrangements. The Victorian Association of Health & Extended Care noted:

28 *Submission 92*, p.4 (Southern Cross Care).

29 *Submission 100*, p.4 (ACAS).

30 House of Representatives Standing Committee on Health & Ageing, *Future Ageing*, March 2005, p.129.

31 *Submissions 203*, p.16 (NSW Aged Care Alliance); 209, p.2 (Community Care Coalition); 170, p.17 (ACS).

32 *Submissions 173*, p.8 (ACSA); 170, pp.16-17 (ACS).

Community Care as well as being preventative, is the most economically efficient and socially effective model of care. It improves people's lives and prevents admissions to residential care facilities. It literally is the way of the future.³³

6.49 Evidence indicates that the community care system is not meeting all the needs of Australians who currently require it. Specific problems identified include the following:

- there are inadequate levels of service provision – 'For some years the Queensland Government has been concerned about the adequacy of community aged care, the multiplicity of Commonwealth Government programs and the absence of choice for frail older people'.³⁴
- services are fragmented – currently there are 17 separate Commonwealth funded programs providing community based care services. In addition the States fund separate programs – in Victoria alone there are 42 different State and Commonwealth funded programs.³⁵
- services are often difficult to access and they are unevenly distributed across the country;
- there is a complex mix of services that are difficult to access;
- there is evidence of considerable unmet need and there are waiting lists for many services;
- there is a lack of case management of clients to follow through with care plans.

6.50 Submissions commented on the complexity of community care programs:

Community care is a complex matrix of services and funding streams that is difficult for the most experienced person to negotiate. At a time when we are encouraging our older people and people with disabilities to plan their own care, or remain in their own homes and communities it is becoming more difficult to do so. The system is confusing for people to access and is administratively inefficient for Governments and service providers.³⁶

The sheer complexity of the community care system and its plethora of programs can be defeating for people needing to access the system...This complexity for consumers is a barrier in itself and creates unnecessary hardship, inequities and inconsistencies for consumers and families.³⁷

33 *Submission* 150, p.21 (VAHEC).

34 *Submission* 193, p.18 (Queensland Government). See also *Submissions* 101, p.5 (MAV); 241, p.1 (Legacy).

35 *Submission* 150, pp.20-21 (VAHEC).

36 *Submission* 201, p.25 (ANF).

37 *Submission* 203, p.16 (NSW Aged Care Alliance).

6.51 Submissions noted that average levels of service provision under HACC is very low. In 2002-03, individuals on average received 38 minutes of domestic service per week, 67 minutes of personal care, 108 minutes of respite care and 16 minutes of nursing care.³⁸ In terms of service intensity, data indicate that in 2002-03, 45 per cent of HACC clients received only one type of assistance; a further 24 per cent of clients received two assistance types and only 14 per cent received three assistance types.³⁹ Data for 2003-04 indicate no change with regard to service intensity compared with 2002-03 figures.⁴⁰

6.52 These figures graphically illustrate the inability of the community care system to provide adequate support for those currently requiring assistance. Instead, the rationale appears to be to limit the time available to each client in order to provide as many people as possible with some service. Pensioner groups reported that many older people are either unable to access necessary services or have had their services cut back. COTA National Seniors stated that seniors report that they have difficulty in obtaining services, especially household support, community transport, gardening and home maintenance and essential home modification.⁴¹

6.53 Evidence indicated that HACC services are in danger of losing their preventative focus. One submission commented on 'the lack of capacity to provide preventative services for low care clients because of the necessity to attend to those with higher care needs who are unable or do not wish to access residential services'.⁴² Another submission noted that HACC services are often now responding to crisis situations rather than responding to the ongoing needs of clients.⁴³

6.54 Submissions noted that the level of services are inadequate for those with more complex needs.⁴⁴ The Aged Care Assessment Service Victoria commented that there has been 'a progressive reduction of flexibility in the provision of generic HACC services as provider agencies move towards setting limits on the number of hours of service clients can expect from the HACC system. This has meant there are now limits to HACC services for high need clients that prevent them from remaining at home'.⁴⁵

6.55 Submissions also noted that many prospective clients in regional and rural areas in particular have limited or no knowledge of the range of HACC services that

38 *Submission* 170, p.16 (ACS of NSW & ACT). See also *Submission* 173, p.7 (ACSA).

39 *Submission* 209, p.1 (Community Care Coalition).

40 HACC, *2003-2004 Annual Bulletin*, p.10.

41 *Submission* 174, p.15 (COTA National Seniors). See also *Submission* 240, p.3 (TPI Association).

42 *Submission* 174, p.15 (COTA National Seniors).

43 *Submission* 115, p.5 (Macarthur Aged & Disability Forum).

44 *Submission* 61, p.11 (Melbourne Citymission).

45 *Submission* 100, p.3 (ACAS).

are available.⁴⁶ Other potential clients are not receiving services. Carers Australia reported that many carers are missing out on services, along with the people that they support, in preference to people without carers – 'it appears, in an environment of resource constraint, people with no family support are being given greater priority for HACC services'.⁴⁷

6.56 A significant concern for providers, especially smaller providers, is the onerous reporting requirements. ASCA noted that there is a growing array of community programs which have created separate reporting requirements. Often the same organisations provide a mix of community care programs and must complete multiple sets of essentially similar information. These different requirements are inhibiting the provision of quality care to individuals while adding to management overhead costs.⁴⁸ Submissions noted that some small organisations are reassessing their commitment to providing services due to the reporting requirements for grants.⁴⁹

Community care review

6.57 Evidence to this inquiry as well as previous reviews of community care indicates that significant reform is needed to the community care system.⁵⁰ In 2002 the Commonwealth Government initiated a review of community care programs to identify strategies that would simplify and streamline current arrangements for the administration and delivery of community care services. The focus of the review is to ensure a community care system in which it is easier for people to access the care they need and within which community care programs are well aligned and interlinked, offering an appropriate continuum of care that is of high quality, affordable and accessible.

6.58 Following a review and consultation process, the Commonwealth Government released *A New Strategy for Community Care – The Way Forward* in August 2004, which outlines a series of steps for reshaping and improving community care. Four broad areas of action have been identified:

- addressing gaps and overlaps in service delivery – including the development of common arrangements for community care programs within a national framework; development of administrative arrangements for the allocation of HACC funds across a three-tiered community care system, based on different levels of care and support; improved alignment of CACP and EACH packages

46 *Submission* 165, p.2 (TasCOSS).

47 *Submission* 111, p.9 (Carers Australia).

48 *Submission* 173, Attachment 2 (ACSA).

49 *Submissions* 125, p.11 (ACS SA & NT); 57, p.13 (UnitingCare Australia).

50 Other reviews by the Myer Foundation, Catholic Health Australia and Aged Care Services Australia concluded that change is needed to reduce system fragmentation and complexity in community care programs.

with other services; and development of consistent eligibility criteria for community care programs.

- easier access to services – including the development of nationally consistent intake assessment for HACC and other community care services; and identification of entry points for easy access by consumers seeking community care services.
- enhanced service management – including the development of a standard financial reporting tool; implementing a quality assurance model for community care programs; and a nationally consistent approach to consumer fees.
- streamlining of Commonwealth Government funded programs – including the alignment of EACH within community care programs; development of a single national contract for dementia initiatives; better integration of initiatives under the Continence Management Strategy; merging the functions of the Aged Care Assessment Team and Dementia Support for Assessment Programs; and applying common arrangements to respite services funded under the National Respite for Carers Program.⁵¹

6.59 The *Way Forward* is based on the adoption of a common approach across all community care programs in key areas such as access, eligibility, common assessment, accountability and quality assurance. The *Way Forward* also involves the development of a new HACC Agreement with the State and Territory Governments, which will be underpinned by the principle of common arrangements. DoHA advised that discussions with the States are continuing in relation to the Agreement and that a draft Agreement is expected to go to Cabinet for consideration in July-August 2005.⁵² State Governments argued that any new HACC Agreement needs to address certain issues such as the need to improve viability for service providers, reduce administrative burdens and provide sufficient funding to meet future demand for services.⁵³

6.60 Evidence to the inquiry generally welcomed the Government's proposals for reform of community care programs arguing that they address many of the deficiencies identified in current programs. One submission noted that within the community care sector there exists:

...in principle agreement with much of the shape of reform proposed...and an urgent need for reform which creates a sensible and flexible program structure to meet consumer needs, reduce consumer confusion and time wasted by services on reporting on, and managing multiple programs.⁵⁴

51 DoHA, *A New Strategy for Community Care: The Way Forward*, August 2004, pp.7-9.

52 DoHA, personal communication, 9.5.05.

53 *Submissions* 193, pp.20-21 (Queensland Government); 200, p.8 (Tasmanian Government); 180, pp.10-11 (Victorian Government).

54 *Submission* 111, p.10 (Carers Australia).

6.61 However, submissions pointed to the need for the Commonwealth to provide a detailed implementation plan and timetable for the reforms.⁵⁵ DoHA advised that major implementation of the reforms will begin in 2006, with some pilot programs and development work being implemented in 2005.⁵⁶ Evidence also pointed to the need for the Commonwealth and the States to work collaboratively in implementing the reforms.⁵⁷

6.62 Evidence indicated that a particularly glaring omission in the *Way Forward* is that it fails to adequately address the need for effective interface between ageing and disability services. ACROD stated that:

At present, bureaucratic and jurisdictional boundaries impede effective service delivery to people with disabilities. For some with long-term disabilities who are growing old, this is particularly so. Such people often search in vain for effective pathways between Commonwealth and State disability service systems, and between aged care and disability service systems.⁵⁸

6.63 The implementation of *The Way Forward* has involved the establishment of compulsory competitive tendering for three respite care programs. Evidence was strongly critical of the process arguing that it was disruptive to services and counterproductive to the development of more integrated service provision. The BSL stated that it 'is causing quite a deal of distress amongst our service users and staff and, again, a lot of paperwork and extra work, taking people away from the direct care requirements'.⁵⁹

6.64 Witnesses noted that competitive tendering does not actually support the client negotiating the myriad services currently available as providers who previously would have collaborated to serve that client are now in a competitive situation, so their desire to collaborate is diminished.⁶⁰ ACSA submitted that 'it certainly cannot in principle lead to better integrated services on the ground. They are already integrated. This is disintegrating them – or at least carries that risk. It is an expensive process'.⁶¹ The Victorian Healthcare Association argued that 'it does not get us any closer to a system that is actually focussed on providing better care for the individual... Tendering...distracts from that'.⁶²

55 *Submissions* 166, pp.15-16 (CHA); 170, p.17 (ACS of NSW & ACT).

56 DoHA, personal communication, 9.5.05. See also *The Way Forward*, p.11.

57 *Submissions* 209, p.2 (Community Care Coalition); 170, p.17 (ACS of NSW & ACT).

58 *Submission* 26, p.2 (ACROD). See also *Committee Hansard* 11.2.05, pp.49-50 (ACROD).

59 *Committee Hansard* 27.4.05, p.6 (BSL).

60 *Committee Hansard* 28.4.05, p.35 (Southern Cross Care).

61 *Committee Hansard* 26.4.05, p.13 (ACSA).

62 *Committee Hansard* 26.4.05, p.13 (Victorian Healthcare Association).

Conclusion

6.65 Evidence to the inquiry indicated that community care programs provide a range of very valuable services to enable older people to live at home. It is, however, evident that significant reform of community care programs is required to achieve a system that better responds to the needs of consumers, care workers and service providers. Evidence indicated that the current system is not providing adequate levels of service; services are fragmented; and there is a complex mix of services that are often difficult to access.

6.66 The Committee notes that the community care review, *The Way Forward*, outlines, in very broad terms, a series of steps for reshaping and improving community care. The Committee supports the aims of the review in addressing gaps and overlaps in service delivery; providing for easier access to services; enhancing service management, including financial reporting; and streamlining of programs. The Committee considers, however, that the Commonwealth needs to provide a comprehensive implementation plan and timetable for the reforms. The Committee also believes that the *Way Forward* strategy needs to address the need for a more effective interface between ageing and disability services. The Committee also considers that the Commonwealth and States and Territories should assess the appropriateness of compulsory competitive tendering for future programs as part of *The Way Forward* strategy.

Recommendation 43

6.67 That the Commonwealth provide a clearly defined timetable for implementing all aspects of *A New Strategy for Community Care: The Way Forward*.

Recommendation 44

6.68 That, in supporting the approach in *The Way Forward* for implementing a more streamlined and coordinated community care system, the Commonwealth address the need for improved service linkages between aged care and disability services.

Recommendation 45

6.69 That the Commonwealth and State and Territory Governments assess the appropriateness of the compulsory competitive tendering process for future programs as part of the implementation of *The Way Forward* strategy.

Informal care

6.70 Evidence to the inquiry indicated that access to informal care plays a critical role in helping individuals who require assistance and support because they are frail, chronically ill or too disabled to remain living in their homes and communities. Most community care occurs in the home, making informal carers the backbone of the Australian community care system.

6.71 The ABS estimates that there are 2.3 million carers in Australia – of these some 450 900 are classed as 'primary carers'. A primary carer is a person of any age who provides the most informal assistance to a person with one or more disabilities.

6.72 The Commonwealth funds two community care programs specifically for carers – the National Respite for Carers Program (NRCP) and the Carer Information and Support Program (CISP).

6.73 Under the National Respite for Carers Program, the following services are provided:

- Commonwealth Carer Resource Centres – These provide information, support and advice to carers on a range of issues.
- Commonwealth Carer Respite Centres – These were originally established in each HACC region across Australia and have the capacity to arrange respite for carers through existing services. There are currently 61 Centres (with 89 outlets in all). These Centres have a pool of funds, called brokerage, to be used to purchase or subsidise short term or emergency respite care.
- Respite services – There are currently 432 community-based respite services delivered to carers and the people for whom they care in a variety of settings, including in-home, day centre, host family, residential overnight cottage-style accommodation and as holiday breaks. In 2003-04 the number of carers assisted by respite services was estimated to be 28 000.
- National Carer Counselling Program – The aim of the program is to address issues specific to carers such as carer stress, grief and loss, coping skills and transition issues. Counselling is provided on a sessional basis by qualified counsellors.

6.74 Overall, Commonwealth funding for the NRCP has increased more than five-fold from \$19 million in 1996-97 to an estimated total of \$104.9 million in 2004-05. The Commonwealth also funds CISP. This program provides carers with information and practical advice about services that can help them in their caring role. Funding for this program for 2004-05 is \$2 million.⁶³

6.75 In the 2005-06 Budget, the Commonwealth announced that it will provide \$207.6 million over four years to support carers by improving access to respite care including increasing the number of respite care services available for carers in paid employment; paying an incentive to encourage residential aged care providers to provide high care residential respite; and increasing the level of respite services available to carers in rural and remote areas.⁶⁴ Support for carers is an essential component of the Commonwealth's community care policy which aims to give people the choice of remaining at home for as long as possible.

63 *Submission 191*, pp.54-55 (DoHA).

64 *Portfolio Budget Statements 2005-06*, Health and Ageing Portfolio, p.82.

6.76 The NRCP complements other services funded by the Commonwealth, aimed at supporting the frail aged and people with disabilities to continue to live in the community, for example the HACC program. While carers are a focus of HACC, as noted above, the NRCP and the CISP are the only two community care programs for which the carer is identified as the main client.

Supporting carers

6.77 Submissions stated that the needs of carers need to be more fully recognised and addressed. The work that carers do in their caring role is constant and exhausting and without assistance carer burnout is likely to lead to increased numbers of older people relying on the formal care system. In particular, the Carers Australia noted that:

- Carer recognition and support needs to be central to *The Way Forward* strategy. Any community care strategy must address the needs of carers by ensuring that community care systems can respond to individual care situations. *The Way Forward* strategy also needs to address the needs of carers of workforce age – the bulk of the carer population.
- Carers have a dual role in the system – they have their own needs for support and assistance to sustain their caring role and they are also key providers of essential services in an unpaid capacity.
- Governments need to address the problem of fewer primary carers and greater numbers of people needing care over the next decades, due to the ageing of the population. This will lead to greater demand and reliance on formal community services to fill the gap in service provision.
- While the uptake of respite services has increased in recent years and respite is delivered in a more flexible manner some problems still exists, especially the need to book respite services often 12 months in advance in some States.⁶⁵

6.78 Submissions noted that that the aged care system is dependent on carers to provide ongoing support for older people – without them the costs of providing care and support to older people would be substantially higher. NSW Health noted that lack of an informal carer, that is, a person living alone, is the single most common trigger for an older person moving into residential care – 'any changes to the balance of care for older people must therefore consider adequate carer supports, together with social changes (such as workforce participation) that impact on people's availability to fulfil the role of "carer"'.⁶⁶

65 *Submission* 111, pp.10-11 (Carers Australia); *Committee Hansard* 11.2.05, pp.50-55 (Carers Australia).

66 *Submission* 202, p.19 (DADHC/NSW Health).

6.79 ACROD also noted that as well as increased support for formal services, a strategy to respond to demand growth for services should include increased support for unpaid carers, without whom demand would be much higher.⁶⁷

Recommendation 46

6.80 That *The Way Forward* implementation strategy recognise the central role of carers in the community care system.

Recommendation 47

6.81 That, while welcoming the increases in Commonwealth funding for carer-specific programs over recent years, the Commonwealth increase funding for these programs through the National Respite for Carers Program and the Carer Information and Support Program.

⁶⁷ *Submission 26*, p.2 (ACROD). See also *Submissions 150*, p.20 (VAHEC); 174, p.16 (COTA National Seniors); 62, pp.5-6 (Gippsland Carers Association).

CHAPTER 7

TRANSITIONAL CARE

There [needs to] be a better integration of aged care and the acute sector to achieve a continuum of care interface to provide the most appropriate and cost effective care.¹

7.1 This chapter discusses the effectiveness of current arrangements for the transition of the elderly from acute hospital settings to aged care settings or back to the community.

7.2 Evidence to the inquiry emphasised the importance of effective Government initiatives at the acute-aged care interface to improve the health and independence of older people who experience a hospital stay, and increase the likelihood of older people returning home rather than entering residential aged care.² The Australian Medical Association illustrated the problem in graphic terms:

Thousands of Australians are trapped in the wrong environment for the type of care they need. There are many people in hospital who no longer need acute care, but are unable to care for themselves at home and cannot access appropriate residential or community care. Similarly, there are people in nursing homes who should be in hospital, and people in the community who ought to be in either hospital to treat particular conditions, or in aged care homes.³

Introduction

7.3 In February 2001, Commonwealth and State/Territory Health Ministers agreed to jointly examine the acute-aged care interface through collaborative work progressed by the all-jurisdiction Care of Older Australians Working Group (COAWG) under the Australian Health Ministers' Advisory Council. Since then COAWG has completed a work program, including a national census of older people in public hospitals, a stocktake of innovative service delivery models at the acute-aged care interface and a mapping exercise of service provision for older people in the hospital and aged care sectors.

7.4 In 2003-04, COAWG developed a National Action Plan for Improving the Care of Older People Across the Acute-Aged Care Continuum, covering the period 2004-2008. Transition care is an important area addressed in the National Action Plan.

1 *Submission 166, p.17 (CHA).*

2 The acute-aged care interface refers to the transition of frail older people from hospitals to home or residential aged care.

3 *Submission 129, p.8 (AMA).*

Commonwealth Government initiatives

7.5 The Commonwealth Government has introduced a number of initiatives to assist frail older people following a hospital episode. These include the Transition Care Program, the Pathways Home Program and the Aged Care Innovative Pool. Through these initiatives, the Government aims to work with the States and Territories to assist older people in making a smooth transition from hospital to home or other long-term care arrangements.

7.6 The need for more flexible care arrangements was highlighted by the Review of Pricing Arrangements in Residential Aged Care (the Hogan Review).

In the main, the current planning arrangements for the release of new aged care places are not able to respond as flexibly as is desirable for the development of new care approaches or to encourage innovation in service delivery. This has been addressed to an extent by the introduction of the Innovative Pool of flexible care places, which has trialled services linked to the acute care-aged care interface, the disability-aged care interface and dementia care. These opportunities should be enhanced.⁴

Transition Care Program

7.7 The Commonwealth in the 2004-05 Budget announced the establishment of a national Transition Care Program to assist older people after a hospital stay. The Government has committed to expanding the Transition Care Program to 2000 flexible aged care places by 2006-07. In the 2005-06 Budget, the Government announced that it will allocate 1500 places by the end of 2005-06.⁵

7.8 Under the program, transition care is provided for older people with low level rehabilitation and support to improve their independence and confidence after a hospital stay. It will also allow older people and their families time to determine whether they can return home with additional support from community care services or need to consider the level of care provided by an aged care home. Transition care is provided in either a residential or community setting. It is estimated that the average period of care will be 8 weeks, meaning that when fully established in 2007 the Program will assist up to 13 000 older Australians each year.⁶

7.9 Recent amendments to the *Aged Care Act 1997* also provide that in cases where residents of aged care homes temporarily leave the facility for transition care, their places will be kept in the facility until their return.⁷

4 Hogan WP, *Review of Pricing Arrangements in Residential Aged Care, Final Report*, Canberra 2004, p.277.

5 *Portfolio Budget Statements 2005-06*, Health and Ageing Portfolio, p.83.

6 *Submission 191*, pp.61-62 (DoHA).

7 *Aged Care Amendment (Transition Care and Assets Testing) Act 2005*.

Pathways Home Program

7.10 The Commonwealth funds the Pathways Home Program under the 2003-08 Australian Health Care Agreements. The Program provides one-off capital and infrastructure funding of \$253 million over five years to assist States and Territories to expand their provision of step down and rehabilitation care.

7.11 The Minister for Health and Ageing, as at July 2004, has approved a range of projects across New South Wales, Victoria, Queensland, Western Australia, South Australia, Tasmania and the ACT, with a total value of \$249 million. The Department of Health and Ageing (DoHA) stated that individually and in combination, these projects will substantially improve the number and quality of rehabilitation and stepdown services that patients will be able to access. All the projects were designed by the States and Territories to ensure that they meet local needs, and the States and Territories will meet the ongoing recurrent costs of their projects.⁸

Innovative Pool

7.12 The Aged Care Innovative Pool, established in 2001-02, is a national pool of flexible care places available for allocation to innovative services outside of the Aged Care Approvals Round. This Pool allows the Commonwealth Government, in partnership with other stakeholders, to allocate places to services that will pilot the provision of aged care services in new ways and via new models of partnership and collaboration.

7.13 Projects that are approved under the Innovative Pool have clear client eligibility criteria, controlled methods of service delivery and are time-limited. Evaluation is an integral element of all projects involving alternative service models.

7.14 Under the Innovative Pool, the Commonwealth and State and Territory Governments provided funding for Innovative Care Rehabilitation Services (ICRS) pilots in 2001-02 and 2002-03. The Commonwealth provided funding for short term personal and nursing care and the State/Territory government provided funding for intensive rehabilitation support for these pilots. In 2001-02 nine ICRS pilots were approved, with a total of 341 places and in 2002-03 a further three ICRS pilots were approved with 52 places.

7.15 In 2003-04, Intermittent Care Services were a focus of the Innovative Pool. The target area of Intermittent Care Services is a broad category focussing on short-term interventions for older people who require additional support to remain in, or return to, their own homes (and avoid entry to residential aged care or hospital) when they experience a change in circumstance or care needs. It is intended to be similar in operation to the short-term, post-hospital rehabilitation category in the 2002-03 ICRS pilots but wider in scope, particularly in terms of the eligible client group it addresses and the services that can be provided. The services to be provided to clients could

8 *Submission 191, p.62 (DoHA).*

include a range of assessment, rehabilitation, treatment, guidance and case management services, intended to determine what the most appropriate long term care arrangement is for the client, and equipping them as well as possible to benefit from that arrangement. In 2003-04, six ICRS pilots were approved, with a total of 396 places.⁹

Effectiveness of programs

7.16 Submissions generally supported these Commonwealth transitional care initiatives although some concerns were raised, especially in relation to the scope of the programs. Catholic Health Australia characterised the programs as 'fragmented' and argued that 'these disparate arrangements will not be sufficient in the medium to longer-term' to meet the needs of the elderly.¹⁰ The Queensland Government also noted that the Commonwealth, in creating special programs, has further fragmented the system and made it more difficult for clients, service providers, and health professional 'to find the right care in the right place at the right time'.¹¹ The Government also commented that while these programs operate at the health and aged care interface they do not resolve the 'key problems' of the shortages of residential aged care beds or the need for high support care packages in the community.¹²

7.17 The Tasmanian Government, while welcoming the Transition Care Program, noted that it will impose 'rigorous reporting requirements around the utilisation of any approved places and a requirement for some level of State contribution'. The Government also argued that the Pathways Home Program is 'restrictive' in its permitted application of funds.

The investment must be in step-down and rehabilitation services, with a strong emphasis toward capital expenditure on new infrastructure or refurbishment of existing infrastructure. As a consequence, innovative proposals for Tasmania targeting local needs cannot be met with funds under this program.¹³

7.18 Submissions emphasised that transitional programs need to be developed in partnership with the different levels of government and non-government community agencies with input from district health services and divisions of general practice to ensure a consistent integrated approach.¹⁴

9 *Submission* 191, p.63 (DoHA).

10 *Submission* 166, p.16 (CHA).

11 *Submission* 193, p.22 (Queensland Government).

12 *Submission* 193, p.3 (Queensland Government).

13 *Submission* 200, p.9 (Tasmanian Government).

14 See, for example, *Submission* 116, p.8 (Blue Care).

State Government and other initiatives

7.19 The States have implemented a number of initiatives to assist with the transition of the elderly from acute hospital settings to aged care settings or back to the community. These initiatives often involve partnerships with hospitals and service providers. The examples referred to below do not cover all programs but are illustrative of a range of initiatives currently undertaken. Initiatives in the private sector have also been undertaken.

7.20 NSW Health has developed a special program, called ComPacks, to provide assisted discharge and post-discharge care to selected in-patients at risk of unnecessarily protracted hospital stays because of high community support needs. Under the pilot program, case managers work with multidisciplinary hospital and community health teams prior to a patient's discharge to identify the patient's in-home care needs and put in place customised community care packages comprising services which will allow the person to return home safely with the support they require.¹⁵

7.21 Submissions commented on the effectiveness of this pilot. ACOSS argued that results of this program to date have been 'very successful' and ACOSS urged the Commonwealth to support such initiatives more widely.¹⁶ Aged and Community Services (ACS) of NSW & ACT also commented that the program 'could potentially be used to facilitate the more effective discharge of older people from hospital to residential care facilities'.¹⁷

7.22 In Victoria, the Government funds a number of initiatives including a well-developed sub-acute service system that includes both an inpatient and community focus – with a particular focus on rehabilitation services and inpatient geriatric evaluation and management services. The Government also has developed a targeted Interim Care Program that provides temporary support and active management of older patients who have completed their acute or sub-acute episode of care, have been recently assessed by an Aged Care Assessment Service and recommended for residential aged care, and are suitable for immediate placement in a residential care facility if a place were available.¹⁸

7.23 One submission noted that the Victorian Government has been 'particularly pro-active' in developing and funding initiatives in the area of transitional care.¹⁹ COTA National Seniors noted that an evaluation of the Interim Care Program found

15 *Submission 202*, p.24 (DADHC/NSW Health).

16 *Submission 172*, p.6 (ACOSS). See also *Committee Hansard* 11.3.05, p.48 (NCOSS).

17 *Submission 170*, p.19 (ACS of NSW & ACT). See also *Submission 204*, p.22 (NCOSS).

18 *Submission 180*, p.13 (Victorian Government).

19 *Submission 66*, p.4 (ANF - Victorian Branch).

that increasing numbers of older people were able to return home following rehabilitation with increased physical functioning and an improved quality of life.²⁰

7.24 In South Australia, the Acute Transition Alliance (ATA) pilot program is a partnership between the State and Commonwealth Governments, public hospitals and aged care providers. The program provides short term community support services and rehabilitation either in a person's own home or temporarily in an aged care facility to improve the physical functioning of older people following a hospital stay. Another program, City Views, provides a residential transition care facility offering specialised rehabilitation and care services to support recovery and provide transition pathways into the aged care system which aims to reduce hospital stays and improve outcomes for older people awaiting residential placement. ACS SA & NT argued that both programs have produced 'excellent outcomes in terms of both benefits to consumers and the hospital system'.²¹

7.25 Another program in South Australia, GP Homelink, is a short-term, community based health crisis intervention program aimed at avoiding older persons' admission to public hospitals. The program works in conjunction with GPs and public hospitals to provide external assistance and support to older people who would otherwise be admitted to hospital. The Hogan Review commented that this project is a 'most useful pilot study' to aid the elderly and 'has much potential for helping the elderly stay in their own homes'.²²

7.26 Submissions noted that there is a continuing need to provide incentives to take these various pilots programs and convert them into mainstream services especially where the programs have demonstrated service improvement and enhanced systems efficiency.²³

7.27 Private sector initiatives were also noted during the inquiry. The Village Life model provides a form of 'transitional care' between independent living and low care nursing. Village Life Ltd, which is a listed public company, provides managed rental accommodation for low income retirees not currently provided for in retirement village facilities, mainly because of financial barriers. Residents pay rent equal to the standard single age pension plus rent assistance and are provided with a furnished unit and daily living assistance in areas such as shopping and meal preparation, home maintenance and heavy laundry. Village Life aims to provide quality lifestyle options with the aim of delaying entry into aged care facilities by approximately five years. At

20 *Submission* 174, p.17 (COTA National Seniors).

21 *Submission* 125, pp.12-13 (ACS SA & NT). See also *Submission* 174, p.17 (COTA National Seniors); *Committee Hansard* 22.2.05, pp.5-6 (ACS SA & NT).

22 Hogan Review, p.257.

23 See, for example, *Submission* 74, p.15 (ANHECA).

present there are 4000 residents in 70 villages throughout Australia. The average age of residents is about 75 years.²⁴

7.28 Some criticisms of the model were made. One witness noted that it did not provide for continuity of care, especially once an elderly person's care needs increased and that the model would be difficult to apply in situations where elderly residents developed dementia.²⁵

Issues

7.29 A number of issues were raised in relation to the acute-aged care interface and these are discussed below.

Discharge planning

7.30 Evidence indicates that for older people early discharge from acute settings back into the community or to residential care can be very difficult unless there is adequate follow-up and access to significant formal and informal support including short and long-term residential and/or community care.²⁶

7.31 Evidence indicated that discharge planning needs to be significantly improved. The Royal District Nursing Service (RDNS) argued that the quality of discharge planning in the acute sector is 'erratic' and frequently fails to recognise the needs and issues faced by clients on their return to their homes. This often leads to distress for clients and their families and even readmission to acute care, an event that may have been avoided with better planning and communication between the acute and community services.²⁷

7.32 NCOSS also noted that it appears to be assumed by hospitals that because community care services exist, there will be adequate supports for people returning home, despite the fact that community care was never intended to respond to the needs of people with sub-acute needs and is not designed as a quick response solution to early discharge.²⁸

7.33 UnitingCare Australia also commented that:

The inadequacy of effective discharge planning for older people leaving hospital and the lack of timely and effective multi-disciplinary intervention in the post-acute phase places a huge burden on the acute hospital system, the residential and community care sectors and, most importantly, on older

24 *Committee Hansard* 18.3.05, pp.23-32 (Village Life).

25 *Committee Hansard* 11.3.05, pp.30-31 (The Benevolent Society).

26 *Submissions* 150, p.23 (VAHEC); 204, p.22 (NCOSS); 79, pp.13-14 (CPSA).

27 *Submission* 51, p.4 (RDNS).

28 *Submission* 204, p.22 (NCOSS).

people and their carers. This burden is exacerbated where people have multiple vulnerabilities, or are isolated from supportive communities.²⁹

7.34 Submissions noted that planning for discharge should be coordinated across a range of medical, allied health and community care professionals and involve the older person, their families and carers.³⁰ ACOSS noted that 'evidence to date is that this rarely occurs in ways that provide security and comfort to the older person, seamless service provision and optimal health and emotional outcomes'.³¹

7.35 The RDNS commented that standardising and formalising of referral protocols between the acute and community sectors may offer some means of addressing this issue and would be an initial step in future developments such as the electronic exchange of information.³²

7.36 COTA National Seniors stated that post discharge community care services are inadequately resourced and poorly planned. COTA argued that the Commonwealth, in conjunction with the States, should develop a national framework for discharge planning and the provision of post acute and convalescent services and facilities, including those in the community – 'they could ensure that adequate discharge, post acute, convalescent and rehabilitation support services back up acute hospital services and facilities. Finally, they could ensure that hospital patient discharge remains a medical decision, not a financial one'.³³

Common assessment processes

7.37 Submissions argued that common assessment procedures for patients need to be implemented across the various health sectors.³⁴

7.38 The Australian Nursing Homes & Extended Care Association (ANHECA) argued that there is significant scope to improve communication between the acute and residential sectors through the adoption of advanced IT systems and the integration of other health-specific IT systems to assist in the communication channels between the two sectors.

7.39 The Association argued that it is essential, that a patient being transferred from acute to residential care have information forwarded at the time of transfer, detailing a recommended medication regime, any diagnostic results, and any suggested treatment regime that needs to be applied in the future. Similarly, a resident

29 *Submission 57*, p.15 (UnitingCare Australia).

30 *Submission 203*, p.19 (NSW Aged Care Alliance).

31 *Submission 172*, p.6 (ACOSS).

32 *Submission 51*, p.4 (RDNS).

33 *Committee Hansard 27.4.05*, p.31 (COTA National Seniors).

34 *Submission 61*, p.12 (Melbourne Citymission).

being transferred from the residential to the acute sector should have information forwarded to the hospital at the time of transfer providing the patients' medical problems and supplying an up-to-date copy of the resident's medical history to avoid unnecessary duplication of patient information on presentation to the hospital.³⁵

7.40 This Committee's report *Healing our Hospitals* noted that there is increasing recognition across the health sector of the potential benefits of electronic health records in improving efficiency, safety and quality of care over paper-based systems.³⁶ At the national level the Commonwealth has been working with the States to develop *HealthConnect*, a national health information network, which is expected to lead to integrated patient records across the health sector. The recent June 2005 Council of Australian Governments (COAG) Meeting noted that the health system could be improved by accelerating work on a national electronic health records system.³⁷

Rehabilitation

7.41 Submissions argued that rehabilitation services for people leaving hospital need to be expanded. The Australian Nursing Federation (ANF) commented that rehabilitation is an essential part of the transition process. Rehabilitation incorporates the skills of a multidisciplinary team such as nurses, medical specialists and allied health professionals. The ANF noted that rehabilitation of older people following an acute health episode requires expert knowledge and care, and any program needs to factor in the resources needed to employ professionals in the field.³⁸

7.42 The NSW Aged Care Alliance stated that geriatric rehabilitation is 'essential' at the interface between acute in-patient care and the next phase, whether it be transitional care, home or residential care. The Alliance also suggested that geriatric rehabilitation facilities should be available for those older people living in the community who have developed disabilities, which may be remediable without admission to the acute hospital system.³⁹

Lack of residential aged care places

7.43 Submissions noted that the effectiveness of transition strategies depends on a number of complementary strategies, including the provision of an adequate supply of residential aged care places.

35 *Submission 74*, pp.14-15 (ANHECA).

36 Senate Community Affairs References Committee, *Healing our Hospitals*, December 2000, p.176.

37 COAG, *Communique*, 3.6.05.

38 *Submission 201*, p.27 (ANF). See also *Submission 170*, p.18 (ACS of NSW & ACT).

39 *Submission 203*, p.19 (NSW Aged Care Alliance).

7.44 The Victorian Government stated that:

The lack of available residential aged care beds, especially high care places, puts extreme pressure on available hospital beds. The effectiveness of transition arrangements for the elderly from acute hospital settings to aged care settings will depend upon the provision of more high care places.⁴⁰

7.45 In the 2004-05 Budget, the Commonwealth provided \$58.4 million over four years to increase the aged care provision ratio from 100 operational places for every 1000 people aged 70 years or over, to 108 operational places. The balance within the provision ratio was also re-weighted to double the proportion of places provided in the community (from 10 to 20 places). The proportion of places provided as high level residential care remained the same – at 40 places for every 1000 people aged 70 years or over. The 2004-05 Budget provided for an estimated 27 900 new aged care places to be allocated over the next three years, including 13 030 in 2004. In the 2005-06 Budget it was announced that a further 11 426 new aged care places will be released in 2005, including 5274 residential places, 4352 CACPs and 1800 flexible care places.⁴¹

7.46 In a joint submission from the Department of Ageing, Disability & Home Care (DADHC) and NSW Health it was noted that while the Commonwealth increased its allocation of residential aged care beds to the States in the 2004 Budget, the inadequate growth in funded residential aged care places and the considerable lag time between residential aged care beds being approved and becoming operational poses problems. At the same time, the demand for assessments of older people for aged care places has been increasing – 'put simply, there are insufficient aged care places to meet the demand'.⁴²

7.47 The Committee questioned DoHA as to why the Government continues to fund low-care places in residential aged care where there is relatively less demand compared with the high level of demand for high care places. The Department argued that the policy of ageing in place 'means that you enter as low care and then you become high care'.⁴³ The Committee questioned this argument noting that while more aged people are using CACPs or HACC services, when they enter residential aged care they are increasing entering as high care residents.

7.48 The Department provided data that shows that of those that entered permanent residential aged care in 2002-03, 61 per cent of admissions were at the high care level and 38 per cent were at the low care level. The Department stated that not all people entering residential aged care at the low care level become high care residents. Of those that enter care at the low care level, 65 per cent move to high care and 35 per

40 *Submission 180*, p.12 (Victorian Government).

41 *PBS 2005-06*, Health and Ageing Portfolio, p.83.

42 *Submission 202*, pp.22-23 (DADHC/NSW Health).

43 *Committee Hansard 11.2.05*, p.77 (DoHA).

cent are discharged while still at the low care level. Of those who do move to high care, the average period in low care is 35 months.⁴⁴

Co-ordinated approach

7.49 Evidence suggests that transitional care needs a more coordinated and strategic policy and funding commitment to meet future needs. DoHA noted that the acute-aged care interface is one of a number of areas where Commonwealth funded and State/Territory funded programs intersect and acknowledged that 'there are significant opportunities for the Australian Government and States and Territories to work together to ensure better outcomes for older people faced with this transition'.⁴⁵

7.50 The recent June 2005 COAG Meeting acknowledged that the elderly face problems at the interfaces of different parts of the health system and recognised that the health system could be improved by:

- simplifying access to care services for the elderly and people leaving hospital;
- helping public patients in hospital waiting for nursing home places; and
- improving the integration of the health care system.⁴⁶

COAG agreed that senior officials would consider these ways of improving the health system and report back to it in December 2005 with a plan of action to progress these reforms.

7.51 Submissions noted that progress towards a continuum of care for older people requires strategies for the integration of primary care, community care, health promotion, rehabilitation, acute care, sub-acute care and residential care.⁴⁷

7.52 State Governments and departments commented that the division of Commonwealth-State responsibilities in the areas of aged care and health poses difficulties in implementing effective transitional care programs. The Queensland Government argued that arrangements for these programs remain 'fundamentally flawed' – 'for many years there have been significant disputes between the two levels of government over the interface between acute and residential care'.⁴⁸

7.53 DADHC/NSW Health noted that the Commonwealth needs to focus on fundamental reforms at the health and aged care interface and adopt a 'whole-systems' approach.

44 *Submission* 191, Supplementary Information, 26.5.05 (DoHA).

45 *Submission* 191, p.61 (DoHA).

46 COAG, *Communique*, 3.6.05.

47 *Submissions* 173, p.9 (ACSA); 150, p.23 (VAHEC). See also *Committee Hansard* 23.2.05, pp.3-4 (Centre for Research into Aged Care Services).

48 *Submission* 193, p.22 (Queensland Government).

What is required is an effective whole-systems approach to health and aged care...The progression in program and service integration across acute care, residential care and community care for older people has been slow and generally services and funding arrangements still remain inevitably fragmented, complex and inflexible.

...[without change] the challenge to manage growth in demand efficiently, service duplication and gaps, and ensuring older people have access to services in the right place and at the right time will continue. The cost shifting between jurisdictions, and the requirement to focus resources on managing program complexities, will also continue.⁴⁹

7.54 The Hogan Review also commented generally on the duplication and overlap in the delivery of services to the aged.

Where programs are intertwined to the extent that health and aged care services are, it is essential that significant effort is expended on minimising overlap and duplication, providing a single point of access for consumers and maximising coordination and communication.⁵⁰

7.55 The review argued that enhanced service delivery is needed and noted that the following broad principles should be followed, including:

- improvements to lines of communication with the States;
- further development of, and support for, joint pilot programs such as the Acute Transition Alliance and flexible funding options; and
- further consideration and development of joint Commonwealth-State Government programs, where the Commonwealth contributes funding to a greater or lesser extent and the State delivers the program.⁵¹

Conclusion

7.56 A number of initiatives have been undertaken at the Commonwealth and State levels towards improving the effectiveness of current arrangements for the transition of older people from hospital settings to aged care settings or back to the community. While these initiatives are welcome, evidence suggests that a more co-ordinated approach needs to be adopted between different levels of government to address a system that remains fragmented and ill-equipped to meet the transitional care needs of the elderly now and into the future.

7.57 Evidence suggests that in a number of areas from discharge planning, assessment procedures and rehabilitation services significant improvements are needed. The effectiveness of transitional programs also depends on a number of complementary strategies, including the provision of an adequate supply of residential

49 *Submission 202*, pp.21-22 (DADHC/NSW Health).

50 Hogan Review, p.260.

51 Hogan Review, p.261.

aged care places. Both Commonwealth and State and Territory Governments need to work together collaboratively towards the implementation of a system that delivers a continuum of care providing the most appropriate and cost effective care across the acute-aged care interface.

Recommendation 48

7.58 That the Commonwealth and the States and Territories improve coordination in the development and implementation of transitional care programs, and that the development of programs include input from the community sector and health professionals.

Recommendation 49

7.59 That the results of innovative pilot programs funded by the Commonwealth and the States and Territories be widely disseminated and that mechanisms be developed to coordinate information about these pilots across jurisdictions so that innovative models of transitional care can be more readily developed based on these models.

Recommendation 50

7.60 That, the Commonwealth, in conjunction with the States and Territories, develop a national framework for geriatric assessment and discharge planning and the provision of post-acute and convalescent services and facilities, including community services; and that discharge planning be coordinated across a range of medical, allied health and community care professions and involve the patient, their family and carers in the development of these plans.

Recommendation 51

7.61 That common assessment procedures for patients be implemented across the various health sectors so that medical records and diagnostic results can be easily transferred across these sectors.

APPENDIX 1

LIST OF PUBLIC SUBMISSIONS, TABLED DOCUMENTS AND OTHER ADDITIONAL INFORMATION AUTHORISED FOR PUBLICATION BY THE COMMITTEE

- 1 McEvoy, Mr John Myles (VIC)
- 2 Shoalhaven Community Options Program (NSW)
- 3 Spencer, Ms Geraldine (ACT)
- 4 Addicott, Ms Glenda (VIC)
- 5 Crofton, Ms Christine
- 6 Samuels, Mr Anthony (NSW)
- 7 Williams, Ms Nuala
- 8 Horton House (NSW)
- 9 Foy, Ms Gayl (NSW)
- Supplementary information*
- Additional information dated 17.12.04
- 10 Smith, Ms Vicky (VIC)
- 11 Nirta, Ms Cathy (SA)
- 12 Amato, Ms Rebecca (VIC)
- 13 Inner West 5 Home and Community Care (HACC) Forum (NSW)
- 14 Winterton, Dr Peter (WA)
- 15 Howes, Mr Ian (VIC)
- 16 Older Persons Action Centre (VIC)
- 17 Hellard, Ms Janine (VIC)
- 18 Hunter Brain Injury Service (NSW)
- 19 Healthy Ageing Project of Metropolitan Domiciliary Care (SA)
- Supplementary information*
- Healthy Ageing Nutrition Project provided at hearing 22.2.05
- 20 Etchells, Ms Richelle (WA)
- 21 Name withheld
- 22 Habourside Haven Villages (NSW)
- 23 West, Ms Raelene (VIC)
- 24 McCusker, Dr Elizabeth (NSW)
- 25 Nambucca Valley Community Services Council Inc (NSW)
- 26 ACROD Limited (ACT)
- 27 Thompson, Mr Rod (NSW)

- 28 Price, Dr Kay; Alde, Ms Pamela; Provis, Dr Chris; Harris, Dr Roger; Stack, Dr Sue (SA)
- 29 Stewart, Ms Nell (VIC)
- 30 Best, Ms Donna (QLD)
- 31 Royal Rehabilitation Centre Sydney (NSW)
Supplementary information
- Summary of opening statement provided at hearing 19.8.04
- 32 Greenacres Association (NSW)
- 33 Deckys, Ms Dian (QLD)
- 34 Deckys, Mr Aaron (QLD)
- 35 Hunter Brain Injury Respite Options Inc (NSW)
- 36 Silver Chain (WA)
Supplementary information
- Info sheet on Home Independence Program provided at hearing 23.2.05
- 37 Centre for Research into Aged Care Services (WA)
Supplementary information
- Two papers on improving health and quality of life of older people provided at hearing 23.2.05
 - Additional information received following the hearing dated 23.02.05; 1.3.05 and 7.3.05
- 38 Stanley, Ms Ingrid (SA)
- 39 Patricia Gladwell Aged Care Service (VIC)
- 40 Boardman, Mr Peter (VIC)
- 41 Southern Health (VIC)
Supplementary information
- ABI Slow to Recover program provided at hearing 26.4.05
- 42 Motor Neurone Disease Association of NSW (NSW)
- 43 Ethnic Child Care Family and Community Services Co-op (NSW)
- 44 National Centre for Vocational Education Research Ltd (NCVER) (SA)
- 45 Winkler, Ms Dianne (VIC)
McKay, Dr Roderick & McDonald, Ms Regina (NSW)
Supplementary information
- Additional information received 30.5.05
- 46 McKay, Dr Roderick & McDonald, Ms Regina (NSW)
Supplementary information
- *How to help depressed older people living in residential aged care*, article from International Psychogeriatrics provided at hearing 11.3.05

-
- 47 Karingal Inc (VIC)
Supplementary information
- Presentation in response to ToR (c) provided at hearing 26.4.05
- 48 Elphick, Mrs Beverley (ACT)
- 49 Townley, Ms Faye (VIC)
- 50 Kilmore & District Hospital (VIC)
- 51 Royal District Nursing Service (VIC)
- 52 Brotherhood of St Laurence (VIC)
- 53 Ashfield Municipal Council (NSW)
Supplementary information
- Additional information received following the hearing dated 13.09.04
- 54 St Bartholomew's House Inc (WA)
- 55 Chrzescijanski, Ms Deirdre (QLD)
- 56 Younger People in Aged Care Alliance (QLD)
Supplementary information
- Additional information received 4.5.05 following hearing
- 57 UnitingCare Australia (ACT)
Supplementary information
- Opening statement provided at hearing 11.2.05
- 58 Palliative Care Victoria Inc (VIC)
- 59 Health Services Union (NSW)
- 60 Darwin Community Legal Service Aged & Disability rights Team (NT)
- 61 Melbourne Citymission (VIC)
- 62 Gippsland Carers Association Inc (VIC)
- 63 Australian Huntington's Disease Association (NSW) Inc (NSW)
- 64 Kapp, Ms Robyn (NSW)
- 65 Langdown, Mr Nathan (QLD)
- 66 Australian Nursing Federation (Vic) Branch (VIC)
Supplementary information
- Letter to ANF from member re unpaid entitlements provided at hearing 27.4.05
 - Additional information received following hearing dated 10.5.05
- 67 Barwon South West Acquired Brain Injury Network (VIC)
- 68 Brain Tumour Australia Inc (ACT)
- 69 Multiple Sclerosis Society of New South Wales (NSW)
Supplementary information
- Additional information following hearing , dated 19.8.04
- 70 Office of the Public Advocate, South Australia (SA)
- 71 Royal College of Nursing, Australia (RCNA) (ACT)

- 72 Australian Physiotherapy Association (APA) (VIC)
Supplementary information
- Info folder on physiotherapy for older Australians in residential aged care facilities and APA standard for minutes of physio care provided at hearing 27.4.05
- 73 Benetas (VIC)
- 74 Australian Nursing Homes and Extended Care Association Limited (ANHECA) (ACT)
- 75 Mental Health Co-ordinating Council (NSW)
- 76 Witherby, Mr Angus (NSW)
- 77 Motor Neurone Disease Association of Victoria Inc (VIC)
- 78 Ballarat District Nursing & Healthcare Inc (VIC)
- 79 Combined Pensioners and Superannuants Association of NSW Inc (NSW)
- 80 Australian Society for Geriatric Medicine (NSW)
Supplementary information
- Additional information received following the hearing dated 1.9.04
- 81 Spinal Cord Injuries Australia (NSW)
- 82 Ethnic Communities' Council of Victoria Inc (VIC)
- 83 Giles, Ms Renee (VIC)
- 84 Cox, Mr Ian (VIC)
Supplementary information
- Statements of concern and book 'To Helen with love' provided at hearing 26.4.05
- 85 Carrington Centennial Trust (NSW)
- 86 Bloor, Geoffrey on behalf of a group of social workers in Adelaide southern metropolitan area (SA)
- 87 Australian Huntington's Disease Association (National) (NSW)
- 88 Geriaction (NSW)
- 89 Nurses Board of Western Australia (WA)
- 90 Villamanta Legal Service (VIC)
- 91 McRae, Mrs Jackie (NSW)
Supplementary information
- Additional information received dated 20.01.05
- 92 Southern Cross Care (Tasmania) Inc (TAS)
Supplementary information
- Additional information received following hearing dated 3.5.05
- 93 Ginnivan, Mr Denis (NSW)
- 94 Lyndoch Residential & Community Care (VIC)
- 95 Queensland Nursing Council (QLD)
- 96 Cardinia Shire Council (VIC)
- 97 Ryan, Ms Margaret (VIC)

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- 98 Resthaven Incorporated (SA)
- 99 Habermann, Mr Daniel (QLD)
- 100 Aged Care Assessment Service Victoria (VIC)
- 101 Municipal Association of Victoria (VIC)
Supplementary information
- Additional information following hearing received 10.5.05
- 102 Neuro-Oncology Group of NSW (NSW)
Supplementary information
- AIHW stats re disability incidence by age provided at hearing 11.3.05
- 103 Ryan, Ms Moira (NSW)
- 104 Osborn Sloan & Associates Pty Ltd (VIC)
- 105 Aged Care Standards and Accreditation Agency Ltd (NSW)
Supplementary information
- Additional information received 27.5.05
- 106 Baw Baw Shire Council (VIC)
- 107 Moseby, Ms Sally (VIC)
- 108 Saltarelli, Ms Lynda (VIC)
- 109 Brain Injury Association of Tasmania (TAS)
- 110 Brain Injury Rehabilitation Unit, Liverpool Health Service (NSW)
Supplementary information
- Copy of a draft report *Forced Choices: Accommodation in NSW for adults with high care needs after Traumatic Brain Injury*, commissioned Motor Accident Authority provided following hearing, received 8.6.05
- 111 Carers Australia (ACT)
- 112 Ward, Mr John (NSW)
- 113 Kelly, Ms Dianne (QLD)
- 114 Lutheran Aged Care (NSW)
- 115 Macarthur Aged & Disability Forum (NSW)
- 116 Blue Care (QLD)
- 117 Lismore City Council (NSW)
- 118 Alzheimer's Australia (ACT)
- 119 ABI Behaviour Consultancy (VIC)
- 120 Adelaide North East Division Regional Medication Advisory Committee (MAC) (SA)
Supplementary information
- Papers: Accurate Therapy from Acute Care to Community, Owing Scripts in residential Aged Care; Quality Use of Medicines in Residential Aged Care provided at hearing 22.2.05
 - Additional information received following hearing dated 7.3.05

- 121 Office of the Public Advocate, Vic (VIC)
- 122 Health Services Union of Australia (VIC)
Supplementary information
- Additional information received following hearing dated 2.5.05
- 123 Nicholson, Noreen and co-signatories (VIC)
- 124 LHMU (Liquor Hospitality and Miscellaneous Union) (NSW)
Supplementary information
- Opening statement and personal statements by Sandra Leggieri, Stan Rosenberg, Jane Slater and Bill Morgan-Harry; Phone-in survey and NACA Principles for staffing levels and skills mix in aged care settings provided at hearing 18.3.05
 - Additional information dated 27.4.05 provided following hearing 18.3.05
- 125 Aged and Community Services SA&NT (SA)
Supplementary information
- Additional information following hearing dated 4.3.05
- 126 Inability Possability Incorporated (VIC)
Supplementary information
- Young people with an ABI requiring high levels of care provided at hearing 26.4.05
- 127 Australian Nursing and Midwifery Council (ACT)
- 128 Hudson, Associate Professor Rosalie (VIC)
Supplementary information
- Supplementary submission received 13.01.05
- 129 Australian Medical Association Limited (ACT)
Supplementary information
- Opening statement provided at hearing 11.2.05
- 130 Elleray, Mr John (NSW)
- 131 Underwood, D (QLD)
- 132 Cullen, Ms Carol (QLD)
- 133 Gilbert, Ms Cherrilyn (QLD)
- 134 Davis, S J (QLD)
- 135 Stewart, Ms Tess (QLD)
- 136 Massie, Mrs M (QLD)
- 137 Cheah, Dr James W (QLD)
- 138 Moir, Mr Simon (QLD)
- 139 Owers, Mr Anthony and Owers, Mrs Christine (NSW)
- 140 Owers, Mr Noel (QLD)
- 141 Gromm, Mr Suewyan (QLD)
- 142 Schmitz, Ms Margaret (QLD)
- 143 Owers, Mr Gregory (QLD)
- 144 Martin, Ms Teresa (QLD)

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- 145 Griffin, D J (QLD)
- 146 Bainbridge, M (QLD)
- 147 Kelly, Ms Sarah (QLD)
- 148 Thomas, Mr Darren (QLD)
- 149 Fuller, Mr Gordon
Way-Fuller, Mrs Margaret
Way, Mr Cameron (NSW)
- Supplementary information*
- Additional information dated 28.2.05 and 1.3.05
- 150 Victorian Association of Health & Extended Care (VAHEC) (VIC)
- 151 Mullett, Mr Doug (VIC)
- 152 Warn, Ms Patti (NSW)
- 153 Read, Ms Lorraine (NSW)
- 154 Morgan, Ms Jean (NSW)
- 155 National Disability Administrators (QLD)
- 156 ParaQuad Victoria (VIC)
- 157 Headway Victoria (VIC)
- 158 Advocacy Tasmania (TAS)
- 159 Tandara Lodge Community Care Inc (TAS)
- 160 National Alliance of Young People in Nursing Homes (VIC)
- Supplementary information*
- Supplementary submission dated 15.4.05
 - Statement by and correspondence about Ms Vicki Smith provided at hearing 26.4.05
 - Additional information dated 30.5.05
- 161 Kendig, Professor Hal (NSW)
- 162 Baptistcare (WA)
- 163 Armstrong, Ms Jan (NSW)
- 164 Physical Disability Council of Australia Ltd (PDCA) (QLD)
- 165 Tasmanian Council of Social Service Inc (TasCOSS) (TAS)
- 166 Catholic Health Australia (ACT)
- Supplementary information*
- Opening speech notes provided at hearing 11.2.05
- 167 ACT Disability, Aged and Carer Advocacy Service Inc (ADACAS) (ACT)
- Supplementary information*
- Supplementary submission received 7.2.05
 - Additional information following hearing 11.2.05, dated 1.4.05
- 168 Department of Family and Community Services (ACT)
- Supplementary information*
- Additional information received 20.6.05

- 169 Ball, Ms Alaine (VIC)
- 170 Aged and Community Services Association of NSW & ACT (NSW)
Supplementary information
- Additional information received following the hearing dated 4.3.05
- 171 O'Sullivan, Mr Damian (VIC)
- 172 Australian Council of Social Service (ACOSS) (NSW)
- 173 Aged and Community Services Australia (VIC)
- 174 COTA National Seniors (VIC)
- 175 MS Society of Victoria and Australian Home Care Services (VIC)
- 176 Barker, Ms Helen (VIC)
- 177 Barker, Ms Angela (VIC)
- 178 Ethnic Communities' Council of NSW (NSW)
- 179 NSW Nurses' Association (NSW)
- 180 Victorian Government (VIC)
Supplementary information
Reports:
- Strategic Directions in Assessment Victorian HACC Program, October 2004
 - Ideas for the future of community care in Victoria, August 2004
 - Who gets HACC, A statistical overview in Victoria 2002-03
 - Response to issues raised By the Commonwealth's Community Care Review, October 2003
 - Improving care for older people, 2003
- provided at hearing 27.4.05
- 181 Public Advocate – Queensland (QLD)
Supplementary information
- Further submissions provided at hearing 18.3.05
- 182 Victorian Healthcare Association Limited (VIC)
- 183 McKenna, Ms Lucille (NSW)
- 184 Dietitians Association of Australia (ACT)
- 185 Nolan, Ms Mary (VIC)
Supplementary information
- Additional information received 1.2.05 and 7.4.05
 - Statement provided at hearing 26.4.05
- 186 Queensland Nurses Union (QLD)
Supplementary information
- Further submissions and article on nursing workloads: the result of a study of Queensland nurses provided at hearing 18.3.05
- 187 Benevolent Society (NSW)
- 188 Headstart Community Access Programme Inc (NSW)

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- 189 Queensland Divisions of General Practice (QLD)
- 190 HOPES Inc (TAS)
Supplementary information
- Additional information following hearing 28.4.05, dated 2.5.05
- 191 Department of Health and Ageing (ACT)
Supplementary information
- Additional information following hearing 11.2.05, dated 18.2.05 and 26.5.05
 - Additional information received 20.5.05, 29.5.05 and 20.6.05
- 192 Disability Services Commission Western Australia (WA)
- 193 Queensland Government (QLD)
- 194 Curran, Ms Roslyn (NSW)
- 195 Horniblow, Mrs Barbara (VIC)
- 196 Aged Care Queensland Incorporated (QLD)
- 197 Wide Bay Division of General Practice (QLD)
- 198 Aged Care Lobby Group (SA)
Supplementary information
- Additional evidence and Issues of concern provided at the hearing 22.2.05
 - Supplementary submission received 21.6.05
- 199 Care Leavers of Australia Network Inc (CLAN) (NSW)
- 199 Care Leavers of Australia Network Inc (CLAN) (NSW)
- 200 Tasmanian Government (TAS)
- 201 Australian Nursing Federation (ANF) (ACT)
Supplementary information
- Wage parity table and Nursing workforce in Australia, September 2004 provided at hearing 11.2.05
- 202 Department of Ageing, Disability & Home Care and NSW Health (NSW)
Supplementary information
- Overheads relating to submission provided at hearing 19.8.04
- 203 The NSW Aged Care Alliance (NSW)
Supplementary information
- Briefing notes on traineeship for ENs in aged care provided at hearing 11.3.05
- 204 Council of Social Service NSW (NCOSS) (NSW)
- 205 Victorian Brain Injury Recovery Association Inc (VBIRA) (VIC)
Supplementary information
- Introductory statement, 'Making New Connections', assessment and entry to nursing homes and hostels of younger people with disabilities provided at hearing 26.4.05
- 206 NSW Retired Teachers Association (NSW)
- 207 Australian Psychological Society (VIC)

- 208 National Rural Health Alliance (NSW)
Supplementary information
• Opening statement provided at hearing 11.2.05
- 209 Community Care Coalition (VIC)
- 210 DSP Australia Inc (VIC)
- 211 Duncan, Dr Norma Jean (NSW)
- 212 Grundell, Erica and Reilly, Mr Richard (VIC)
- 213 Cullinan, Chris (VIC)
- 214 Lions Club of Sunbury Elderly Peoples Home Incorporated (VIC)
- 215 O'Loughlin, Ms Chris (SA)
- 216 Hornberg, Ms Tanya (QLD)
- 217 No submission
- 218 The New South Wales Council for Intellectual Disability (NSW)
- 219 Neill, Ms Tanya (NSW)
- 220 McIntyre, Mr John (ACT)
- 221 Zaharopoulos, Desi
- 222 Gladman, Ms Catherine (ACT)
- 223 Gellatly, Mr Barry and Mrs Jan (VIC)
- 224 Fronditha Care Inc and DutchCare Ltd (VIC)
- 225 Tierney, Dr Joan (VIC)
- 226 McCormack, Ms Eileen (VIC)
- 227 MS Society of Tasmania (TAS)
- 228 National Brain Injury Foundation (ACT)
- 229 The Mary Ogilvy Homes Society (TAS)
- 230 Bennett, Ms Sarah (NSW)
- 231 Schoenheimer, Ms Ruth
- 232 Disability Action Inc (SA)
Supplementary information
• Revised submission provided at hearing 22.2.05
- 233 Anglican Care (NSW)
- 234 Office of the Public Guardian (NSW)
- 235 NSW Catholic Social Welfare Committee (NSW)
- 236 Seadon, Ms Amy (VIC)
- 237 Saul, Mr Edward (NSW)
Supplementary information
• Additional information received on various dates
- 238 Greening, Ms Janine (VIC)

- 239 Sargent, Dr Leisa
Harley, Associate Professor Bill
Allen, Ms Belinda (VIC)
- 240 The Totally and Permanently Disabled Soldiers' Association (NSW)
- 241 Legacy Coordinating Council (VIC)
- 242 Clements, Mr William James and Mrs Marie Edith (NSW)
- 243 Aged Care Crisis Team (VIC)

Additional information

Bentleys MRI (Qld) Pty Ltd and James Underwood and Associates Pty Ltd
The 2003/04 National Residential Aged Care Survey

Brightwater Care Group, WA
Service profile of facilities at Ellison House and Maylands

Doutta Galla Aged Services
Response to comments made at public hearing on 26 April, dated 5 May 2005

MS Society of WA
Information folder

National Aged Care Alliance
Principles for staffing levels and skills mix in aged care settings, December 2004

Village Life Ltd
Information on operations and objectives, 11 March 2005

APPENDIX 2

WITNESSES WHO APPEARED BEFORE THE COMMITTEE AT PUBLIC HEARINGS

Thursday, 19 August 2004

Central Room, Level 2, Mercure Hotel on Broadway, Sydney

Royal Rehabilitation Centre Sydney

Mr Jeff Chan, Director of Community Integration

Australian Huntington's Disease Association

Ms Robyn Kapp, Executive Officer NSW Association and Treasurer National Association

Multiple Sclerosis Society of NSW

Mr Bill Northcote, Chief Executive Officer

Spinal Cord Injuries Australia

Mr Paul Versteegen, Policy Coordinator

Aged and Community Services Association

Mr Paul Sadler, Chief Executive Officer

Australian Society for Geriatric Medicine

Dr Peter Hunter, President Elect

Geriaction

Kate Hurrell, State and National President

New South Wales Department of Health

Dr Richard Matthews, Deputy Director-General, Strategic Development Division

Ms Catherine Katz, Director, Intergovernment and Funding Strategies, Strategic Development Division

Ms Elena Manning, A/g Manager, Intergovernment and Funding Strategies, Strategic Development Division

Health Services Union

Ms Natalie Bradbury, Acting Assistant Secretary

Ms Sheila Hughes, Member

Ms Josie Peacock, Member

Ms Evelyn Fox, HSU Member

Ms Tracey Allen, Member

Aged Care Standards and Accreditation Agency

Mr Mark Brandon, Chief Executive Officer

Mr Ross Bushrod, General Manager Accreditation

Ashfield Municipal Council

Ms Janine Fullin, Community Worker (Aged and Disability Services)

Friday, 11 February 2005

Parliament House, Canberra

UnitingCare Australia

Ms Lin Hatfield Dodds, National Director

Mr Fred Huckerby

Australian Nursing Homes and Extended Care Association (ANHECA)

Mr Rod Young, Chief Executive Officer

Catholic Health Australia

Mr Francis Sullivan, Chief Executive Officer

Mr Richard Gray, Director, Aged Care Services

Ms Margaret Deerain, Manager Policy and Research

Australian Medical Association Limited (AMA)

Dr Mukesh Haikerwal, Vice President & Chair Committee on Care of Older People

Mr Bruce Shaw, Senior Policy Adviser, Aged Care

Mr John O'Dea, Director, Medical Practice

Ms Josie Hill, Policy Adviser

Australian Nursing Federation (ANF)

Ms Jill Iliffe, Federal Secretary

Ms Geraldine Cowin, Assistant Federal Secretary

Royal College of Nursing, Australia (RCNA)

Ms Elizabeth Foley, Director, Policy

Ms Kaye Hogan, Consultant

ACROD

Dr Ken Baker, Chief Executive

Carers Australia

Ms Julie Austin, Senior Policy Adviser

ACT Disability, Aged and Carer Advocacy Service (ADACAS)

Mr Michael Woodhead, Acting Manager

National Rural Health Alliance

Mr Gordon Gregory, Executive Director

Department of Health and Ageing

Mr Nick Mersiades, First Assistant Secretary, Ageing and Aged Care Division

Mr Warwick Bruen, Assistant Secretary, Community Care Branch

Ms Gail Finlay, Assistant Secretary, Quality Outcomes Branch

Ms Alice Creelman, A/g Assistant Secretary, Policy and Evaluation Branch

Mr Stephen Dellar, Assistant Secretary, Residential Programs Management Branch

Dr David Cullen, Executive Director, Financial & Economic Modelling and Analysis Group

Department of Family and Community Services

Mr Roger Barson, Assistant Secretary, Office of Disability

Tuesday, 22 February 2005

Old Methodist Meeting Hall, Adelaide Town Hall, 25 Pirie Street, Adelaide

Aged and Community Services SA & NT

Mr Robert Dempsey, Chief Executive Officer

Mrs Marcia Fisher, Chairperson

Resthaven

Mr Richard Hearn, Chief Executive Officer

Dr Kay Price, School of Nursing and Midwifery, University of South Australia**Aged Care Lobby Group**

Ms Jenny Booth, Chair

Mrs Grace Jackman, Member and Consumer

Office of the Public Advocate

Mr John Harley, Public Advocate

Healthy Ageing Project of Metropolitan Domiciliary Care

Dr Bob Penhall, General Manager, Medical Services

Ms Leah Trotta, Project Manager

Adelaide North East Division Regional Medication Advisory Committee

Professor Andrew Gilbert, Director, Medicines and Research Centre, University of South Australia

Ms Wendy Morey, Clinical Manager, Resthaven

Dr Peter Ford, Member, Regional Medication Advisory Committee

Ms Belinda Loveless, Aged Care Program Coordinator

Disability Action

Mr Phillip Beddall, Member

Mr David Morrell, Member

Wednesday, 23 February 2005

Conference Room, Commonwealth Offices, Level 39 Exchange Plaza, Perth

Centre for Research into Aged Care Services, Curtin University of Technology

Ms Barbara Horner, Director

Nurses Board of Western Australia

Ms Margaret Watson, Chief Executive Officer

Baptistcare

Mr Ken Ridge, Chief Executive Officer

Silver Chain

Mr Ross Bradshaw, Chief Executive

St Bartholomew's House

Ms Lynne Evans, Chief Executive Officer

WA MS Society

Ms Sue Shapland, Senior Manager, Member Services

Friday, 11 March 2005

Central Room, Level 2, Mercure Hotel on Broadway, Sydney

Ethnic Communities' Council of NSW

Ms Edna McGill, Assistant Treasurer

Neuro-Oncology Group of NSW

Professor Michael Barton, Chair

Ms Teresa Simpson, Member

Ms Siobhan Langford, Member

Brain Injury Rehabilitation Unit, Liverpool Health Service

Dr Adeline Hodgkinson, Director

Ms Barbara Strettles, Residential Service Manager

Carrington Centennial Trust

Mr Raad Richards, Chief Executive

Ms Stephanie Penney, Director

Benevolent Society

Ms Barbara Squires, Director, Centre on Ageing

NSW Nurses Association

Mr Brett Holmes, General Secretary

Ms Lynette Flanagan, Member, Branch Delegate and Branch Secretary

Mrs Christina Heath, Member

Ms Lucille McKenna, Councillor and Branch Delegate

Council of Social Service of NSW (NCOSS)

Mr Gary Moore, Director

Ms Christine Regan

Ms Tara Prince, Representative, NSW HAACC issues forum

Ms Sheree Freeburn, Member, NSW Aboriginal Community Care Gathering

NSW Aged Care Alliance

Ms Janet Ma

Mental Health Co-ordinating Council

Ms Ann MacLochlainn, Policy Officer

Ms Vanessa Vaughan, Sydney Support Services Manager, New Horizons Enterprises Ltd

Dr Roderick McKay, Director, Aged Care Psychiatry, Braeside Hospital

Mr Gordon Fuller, Mrs Margaret Way-Fuller & Mr Cameron Way

Ms Gayl Foy

Mrs Jackie McRae

Friday, 18 March 2005

Dandiiir Room, Level 5, Parliament House, Alice Street, Brisbane

Office of the Public Advocate – Queensland

Mr Ian Boardman, Public Advocate

Ms Beverley Funnell, Senior Research Officer

Mr Lindsay Irons, Senior Research Officer

Aged Care Queensland

Mr Don Bain, President

Mr David Angell, Chief Executive Officer

Village Life Ltd

Mr Tony Roberts, Joint Managing Director

Younger People in Aged Care Alliance

Ms Melinda Ewin

Mrs Glenda Grimley, Policy and Research Officer, Cerebral Palsy League of Qld

Mobile Attendant Care Service

Mr Darren Meyers, President

Ms Sharan Hatch, Coordinator

Liquor, Hospitality and Miscellaneous Union (LHMU)

Ms Valda Graham, Assistant Secretary

Ms Sandra Leggieri, Delegate

Mr Stan Rosenberg, Delegate

Mr Bill Morgan-Harry, Delegate

Ms June Slater, Delegate

Queensland Nursing Council

Ms Anne Morrison, Executive Officer

Ms Maureen Thompson, Principal Research & Policy Adviser

Queensland Nurses Union

Ms Gay Hawksworth, Secretary

Ms Anne Garrahy, Professional Officer

Mr Steven Ross, Industrial Officer

Tuesday, 26 April 2005

*St James Court Conference & Function Centre, 12 Batman Street
West Melbourne*

Aged and Community Services Australia

Mr Greg Mundy, Chief Executive Officer

Victorian Association of Health & Extended Care

Ms Sandra Hills, Board Member

Victorian Healthcare Association

Ms Martina Stanley, Senior Policy Officer

Palliative Care Victoria

Mr Kevin Larkins, Executive Director

Southern Health

Mr Greg Young, Executive Director, Primary Care

Ms Bronwyn Harding, Manager, ABI:STR Program

Inability Possability

Ms Megan Atkins, Secretary

Ms Eileen McCormack

Karingal Inc

Dr Brian Donovan, Director, Innovation Unit

Mrs Vanda Fear

Health Services Union

Mr Craig Thomson, National Secretary

Mrs Alicia Anset, Member

Mr William Jacob, Member

Mrs Iva Wilken, Member

Mrs Debra Williams, Member

National Alliance of Young People in Nursing Homes

Dr Bronwyn Morkham, National Director

MS Society of Victoria and Australian Home Care Services

Mr Lindsay McMillan, Chief Executive Officer, MS Society

Mr Alan Blackwood, Manager, Policy & Community Partnerships, MS Society

Ms Deborah Farrell, Residential Services Manager, Australian Home Care Services

Ms Vicky Smith

Motor Neurone Disease Association of Victoria

Mr Rodney Harris, Chief Executive Officer

ParaQuad Victoria

Ms Helen Bryant, General Manager, Community Care

Ms Margaret Cooper, Polio Advisory Committee

Victorian Brain Injury Recovery Association

Mr Allen Martin, Acting Secretary and Treasurer

Professor Barry Rawicki, Past President

Dr Joan Tierney, Executive Committee Member

Ms Susan Vincent, Executive Committee Member

Ms Mary Nolan**Mr Richard Reilly****Mr Jeremy Smith****Mr Ian Cox**

Wednesday, 27 April 2005

*St James Court Conference & Function Centre, 12 Batman Street,
West Melbourne*

Brotherhood of St Laurence

Mr Alan Gruner, Manager, Residential Services

Ms Christine Morka, Manager, Community Care

Melbourne Citymission

Ms Colleen Tenni, General Manager, Aged Care Services

Benetas

Ms Helen Kurincic, Executive Director

Municipal Association of Victoria

Mr Peter Walsh, Director, Policy & Strategy

Ms Clare Hargreaves, Senior Advisor Social Policy

Community Care Coalition

Ms Pat Sparrow

COTA National Seniors

Mr David Deans, Chief Executive Officer

Ethnic Communities' Council of Victoria

Ms Marion Lau, Immediate Past Chairperson

Mr Phong Nguyen, Chairperson

Froniditha Care Inc & DutchCare Ltd

Mr Peter Gogorosis, Chief Executive Officer, Froniditha Care

ANF (Victorian Branch)

Ms Jan Brownrigg, Assistant Secretary

Ms Jill Clutterbuck, Senior Professional Officer

Ms Kate Jackson, Industrial Relations Organiser

Royal District Nursing Service

Mr Dan Romanis, Chief Executive Officer

Ms Carol Jaffit, District Nurse Specialist, Continence

Australian Physiotherapy Association

Ms Cathy Nall, President

Aged Care Assessment Service Victoria

Ms Maureen Smith, Chairperson

Ms Pauline Donaldson, Past Chairperson

Office of the Public Advocate

Dr David Sykes, Manager, Policy & Education

Victorian Government

Mr Chris Puckey, Manager, Policy & Analysis, Aged Care Branch, Department of Human Services

Ms Jeannine Jacobson, Manager, Coordinated & Home Care

Thursday, 28 April 2005

Glenorchy Civic Centre, Cooper Street, Glenorchy, Hobart

Advocacy Tasmania

Ms Hilary Brown, Aged Care Advocate

Mr Kenneth Hardaker, Manager

Southern Cross Care (Tasmania)

Mr Richard Sadek, Chief Executive Officer

Ms Jill Savell, Director, Community Care

Ms Carolyn Wallace, Director of Nursing, Rosary Gardens

Mary Ogilvy Homes Society

Ms Jo Hardy, Chief Executive Officer

Tasmanian Council of Social Service

Mr Mat Rowell, Executive Director

HOPES

Mr David Pearce, President

Ms Sue Hodgson, Vice President

Ms Carolyn Neilsen, Member

Brain Injury Association of Tasmania

Ms Deborah Byrne, Executive Officer

MS Society of Tasmania

Mr Ross Duncan, General Manager

INSPECTIONS

Wednesday, 23 February 2005

Perth

MS Society WA

MS Society Wilson Administration Centre, Wilson for discussions and visit with Mr Marcus Stafford, CEO and Ms Sue Shapland, Senior Manager

Fern River complex, Wilson - a cluster of six villas to support people with MS.

Brightwater Care Group

Ellison House, Orrong Road, Carlisle - facility for people with Huntington's Disease

Maylands, Caledonian Avenue, Maylands - a house for people with acquired brain injury.

The Committee was accompanied by Ms Janet Wagland, Manager, Services for younger people.

Tuesday, 26 April 2005

MS Society of Victoria, 27a Blackwood Street, Carnegie

The Committee visited the MS Society of Victoria home in Carnegie, inspected the facilities and had informal discussions with residents, staff and members of the MS Society executive who had appeared at the public hearing earlier in the day.