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

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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.

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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]

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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

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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

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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.

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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]

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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

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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.
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> 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:

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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

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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]

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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]

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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

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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 oversighted 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:

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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

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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 heath 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

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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 devises 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

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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 reducd 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]

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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 devises 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:

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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]

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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

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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 trained [99]

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]

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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

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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:

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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]

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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 shore 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]

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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

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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]

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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]

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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]

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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

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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]

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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]

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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]

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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]

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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

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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]

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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 NAPYINH 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).

- 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 coming 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 jurisdications work cooperatively to:

- **assess the suitablity 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 Officals 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 responsibilites of all jursidictions 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.