SENATE COMMUNITY AFFAIRS REFERENCES COMMITTEE

INQUIRY INTO AGED CARE

Submission on

- The appropriateness of young people with disabilities being accommodated in residential aged care facilities

- And the extent to which residents with special needs, such as dementia, mental illness or specific conditions are met under current funding arrangements

Submitted by the National Alliance of Young People In Nursing Homes

4 August 2004

***The National Alliance of Young People In Nursing Homes*… a coordinated response to the YPINH problem**

Formed as the result of a Call to Action ratified by the *National Summit on Young People In Nursing Homes in 2002*, the *National Alliance of Young People in Nursing Homes* is comprised of a National Secretariat based in Melbourne, and a series of State and Territory based 'Engine Rooms'. The Secretariat's position is currently coordinated by the *Victorian Young People In Nursing Homes Consortium which includes a range of disability and aged care organization, young people and their families*.

All stakeholder groups are represented in the Alliance's membership, including YPINH, family members and friends, service providers, aged care representatives, members of various national and state based peak bodies, government representatives, and advocacy groups.

Each State and Territory Engine Room operates at a local and State level to raise awareness of the issue of young people living in aged care facilities; and works across jurisdictions to develop sustainable accommodation and support options with government and non-government agencies, YPINH, and other concerned individuals.

As the pre-eminent national voice on this issue, the *National Alliance's* primary objectives are to

- Raise awareness of the plight of YPINH and the urgent need for community based accommodation and support options for young people with high and/or complex care needs
- Work with government and non-government agencies to develop sustainable funding and organisational alternatives that deliver a 'life worth living' to young people living in aged care facilities
- Provide on-going support to family members and friends of YPINH.

Key Commonwealth and State bureaucrats work closely with the Alliance towards resolution of the YPINH issue.

1 Introduction

Every day, a young person with high or complex care needs is placed in an aged care facility somewhere in Australia because the accommodation and support they need does not exist. Some of these individuals are younger than 10 years of age.

At the current rate of entry there will be over 10,000 young people residing in aged care facilities by 2007.

The *National Alliance of Young People In Nursing Homes* does not believe aged care settings are an appropriate option for younger people with disabilities. Yet they are often the only option available to young people with high or complex care needs.

Because aged care facilities are not designed to cater for the very different and more intensive needs of younger people and are certainly not funded to provide for these needs, facilities and staff struggle to provide the care these young people require.

There are a number of reasons why the National Alliance believes residential aged care is unsuited to the growing need for accommodation and support for young people with high and complex care needs. These include that

- Staff do not have the requisite skills and knowledge to care for younger people with Acquired Brain Injuries. Nor are they trained to deal with the specific care needs of other disabilities, such as Multiple Sclerosis, Muscular Dystrophy or Parkinson's disease.
- Aged Care Nursing Homes have a clear lack of rehabilitation orientation.
- The resources needed to purchase appropriate equipment to support the complex care needs of young people do not exist.
- Therapeutic input is required to maintain an individual's physical, cognitive and social functioning. The resources to manage this input are largely unavailable. So too are the resources needed to foster that individual's rehabilitative potential.
- Aged Care Staffing levels are insufficient to maintain and promote independence.

As well as these young people who simply want 'a life worth living' and to become productive members of their communities again, this issue adversely impacts the thousands of frail older Australians who are unable to access the aged care places they need because of the systemic blockage these young people cause. As a result, some of these frail older folk are forced to continue living in situations that are dangerous to their health and threaten their longevity or, alternatively, are forced to live in acute care hospital settings while they wait for an aged care place to become available.

Causing a massive waste of resources and health dollars to the tune of some $372 million nationally every year, this upstream blockage also prevents the acutely ill from accessing the facilities and services meant for them. This, in *its* turn, prevents ordinary Australians from obtaining the health care they need and intensifies hospital waiting lists consequently.

The terms of reference speak of the appropriateness of young people with disabilities being accommodated in residential aged care facilities. Given the wrenching stories of heartache and

difficulty around young people living in residential aged care, inappropriate seems far too gentle a term to apply to these young people – some of them mere children – who are amongst the most vulnerable in our community and simply want the same considerations and care we all aspire to in times of need. When considering the lack of attention and care the existing system gives to their needs, inhumane seems a much more apt term.

The Young People In Nursing Homes issue is symptomatic of a wider failure around systemic service provision and unmet need for young people with high level nursing care needs. Solving this issue will not only provide opportunities for improvements in dignity, independence and meaning to the growing number of young people forced to live in aged care facilities. It will also clear systemic blockages in aged care, health and disability services and return services, facilities and funding to those they are intended to target.

To achieve this, we need to look further than the development of alternative accommodation 'models'. Such a strategy is limited in concept and carries an inherent flexibility that cannot accommodate the changing needs and life goals of young people. The answer lies instead with Young People In Nursing Homes themselves and their family members.

Creating opportunities that are developed around the needs of the individual and that are flexible in their approach to individualized care, has already proven successful. Utilising a person centred planning approach will avoid the creation of further traps for people whose needs do not fit neatly into 'models' of care.

2 Who are young people in aged care (YPINH)

The population of young people living in residential aged care (YPINH) includes individuals with a variety of acquired disabilities. Many have sustained catastrophic injuries in situations where compensation is not available. There is also a significant group who has developed degenerative neurological diseases, requiring an episodic approach to facility based nursing care.[1] Along with these groups there are numbers of people with very diverse presentations, often with few of their needs in common, and from widely varying age groups.

2.1 Catastrophic injuries and events

Some of these catastrophic injuries are sustained in unpredictable health events like asthma or meningitis attacks that result in hypoxic Acquired Brain Injuries (ABI). Some are the result of catastrophic 'accidents', including unprovoked assaults or 'muggings' that leave the young person involved with an ABI; spinal cord or brain injuries developed as a result of diving in shallow water or falling down a flight of stairs; or even viral infections that cross the blood/brain barrier resulting in multiple organ failure and ABI.

Some are also due to the progressive deterioration involved in some degenerative neurological diseases like Multiple Sclerosis, Muscular Dystrophy or Parkinson's Disease. Some are the due to the poor capacity of fault based insurance schemes to provide for rehabilitation and care after catastrophic injury. The scheme run by Queensland's Motor Accident Insurance Commission requires proof of negligence against the owner or driver of the motor vehicle concerned to

[1] It remains a fact that solutions have been more readily found when people have been compensated, and an individualised approach implemented.

sustain claims for compensation and is representative of the sort of fault based scheme that sees young people languish in residential aged care settings without hope of recovery or rehabilitation.[2]

This almost infinite variety of cause declares two stark facts. First, that any one of us could face the predicament of placement in an aged care facility, either personally or through the involvement of a family member or friend. Second, that despite investing significant funds, resources and energy to *saving* lives, we fail to give any thought to sustaining lives *after* a catastrophic event so that lives of dignity and meaning can result.

2.2 YPINH and the Commonwealth State Territory Disability Agreement (CSTDA)

Despite being part of the Commonwealth State Territory Disability Agreement target group, YPINH are unable to access the disability funds and resources that are available under this agreement to all other young individuals with disabilities.

The poor capacity of the CSTDA sector means that state based disability systems which are already struggling to meet demand, fail to address the needs of people who are in Commonwealth funded facilities. This, as well as ongoing jurisdictional conflicts between Federal and State governments around funding across sector 'boundaries' and concomitant responsibility for service provision; and a lack of coordination and cooperation between the health, disability and community care sectors, are the main reasons why YPINH find themselves in aged care facilities.

Recent studies indicate that the population breakdown of young people in aged care with acquired disabilities is

- *Acquired Brain Injury (ABI)* *30%*
- *Physical Disability* *27%*
- *Neurological* *23%*
- *Intellectual/psychiatric* *20%* [3]

It includes a large number of people with high needs without speech who are particularly at risk.

The YPINH target group covers people with disabilities living

- in aged care facilities - both hostels and nursing homes
- in acute care facilities who cannot return home and whose only option is placement in an aged care facility
- at home with aging carers at risk of admission to aged care facilities

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[2] Queensland operates a common law 'fault' based Compulsory Third Party (CTP) scheme, first introduced in 1936. The scheme provides motor vehicle owners with an insurance policy that covers their unlimited liability for personal injury caused by, through or in connection with the use of the insured motor vehicle anywhere in Australia. For the injured third party it provides access to common law, that is, the injured person has a right to approach a law court to seek monetary compensation from the person 'at fault' for the personal injury and other related losses. As a fault based scheme it requires proof of liability, i.e. the injured party must be able to establish negligence against an owner or driver of a motor vehicle. *Consequently, circumstances can arise where, for example, a driver who is wholly at fault in an accident cannot obtain compensation because there is no negligent party against whom a claim can be made.* See http://www.maic.qld.gov.au/ emphasis added.

[3] See *The ABI Strategic Plan*, Department of Human Services, Victoria, 2001.

Currently, people under 65 occupy 5% of residential aged care beds. Data received from providers indicate the majority of younger residents receive RCS level 1-3 subsidies.

The number of YPINH has nearly doubled in the last decade and the rate of increase is likely to grow further in line with the 12% demand increase predicted by the AIHW over the life of the 3rd CSTDA.

As one example, in the latter half of 2003, of the 23, 000 aged care assessments conducted at a major Melbourne teaching hospital, 11.6% were for people < 70. In just one month during that time, 25% of all assessments conducted were for people < 70.

Allowing for a number of people assessed being between 65 and 70, there is a greater number of younger people being assessed (11.6%) than the current number of young people living in the aged care system (5%). A significant number of these are at the highest level of need.

Although the rate of increase nationally had flattened in recent years, we are currently seeing a spike in numbers that is set to intensify. In the two-month period from January to March 2004, an additional 73 young people entered aged care nursing homes nationally, taking the total from 6188 to 6261 in just one 8 week period.

The lack of funding growth in the CSTDA is already significantly increasing pressure on the aged care sector, and the Alliance expects these numbers to increase at a faster rate in the next 5 years.

The following figures show the rate of increase across all states, indicating current numbers of YPINH by state (Figure 1), and the steady growth in numbers over the last fourteen years nationally (Figure 2). Figure 2 clearly shows the beginning of the spike in numbers that will see 10,000 YPINH by 2007 if nothing is done.

Table 1 People under 65 in residential aged care by jurisdiction as at March 2004

State/Age	0-9	10-19	20-29	30-39	40-49	50-59	60-64	<45	<50	<65
NSW	0	0	20	73	300	932	897	198	393	2222
VIC	2	1	12	43	171	649	658	115	229	1536
QLD	0	3	7	52	166	571	499	120	228	1298
SA	0	0	5	12	52	162	197	35	69	428
WA	0	1	5	9	59	205	209	42	74	488
TAS	0	0	1	3	19	63	75	11	23	161
NT	0	0	0	2	10	37	24	6	12	73
ACT	0	0	0	0	3	16	36	0	3	55
Australia	**2**	**5**	**50**	**194**	**780**	**2635**	**2595**	**527**	**1031**	**6261**

Source: Department of Health and Ageing

Table 2 Cumulative totals by Jurisdiction 1990-2004

Date	ACT	NSW	NT	QLD	SA	TAS	VIC	WA	*Cum. Total*
1990	33	1,541	31	601	323	72	604	326	3,531
1992	39	1,766	39	712	371	106	789	387	4,209
1994	71	1,951	58	892	350	125	1,035	445	4,927
1996	53	2,027	63	948	344	129	1,177	428	5,169
1998	57	2,167	65	1,141	312	153	1,410	477	5,782
2000	37	2,299	67	1,205	325	149	1,433	497	6,012
2001	41	2,279	61	1,219	346	136	1,414	485	5,981
2002	48	2221	65	1293	381	155	1439	467	6,069
2003	52	2204	73	1273	388	154	1444	479	6,067
2004	**55**	**2222**	**73**	**1298**	**428**	**161**	**1536**	**488**	**6261**

Source: Department of Health and Ageing

3 National Conventions on the YPINH issue

Over the last two years, two major conventions on this issue have taken place: a National Summit in May 2002 and a National Conference in 2003.

Both events involved the participation of young people living in nursing homes, their family members and friends, as well as representatives from all stakeholder groups including federal and state politicians, peak bodies, government and non-government agencies in the disability, health and aged care sectors.

3.1 National Summit on Young People in Nursing Homes 2002

Held in May 2002, the *National Summit on YPINH* was the first national event to bring attention to this matter. 180 participants represented governments, consumers, providers and advocates in every State and Territory of the Commonwealth.

The Summit agreed on a *Call for Action* that is attached to this submission.[4] It highlighted the need for Commonwealth leadership to solve a national problem, as well as calling for innovation, partnership and resources.

3.2 Unlocking Potential…From Vision to Reality. A National Conference on Alternatives for Young People In Nursing Homes 2003

Over 500 participants from every stakeholder group attended this inaugural conference. With three streams of presentations, speakers described a variety of community based accommodation and support models that have succeeded in enabling YPINH to become productive members of their communities, and indicated the systemic and organisational changes needed to make more of the same available.

[4] See Appendix 7.4, page 37.

Young people, who had successfully moved from aged care facilities to community based living arrangements, spoke of their journeys and what it had meant to regain independence and dignity in living. Young people living in nursing homes also spoke of what they wanted and their strong need to have lives of purpose and result…lives worth living.

The conference concluded that the development of a sustainable way forward depended on two crucial advances. The first was the urgent need for a national no fault insurance scheme to cover catastrophic injuries and the onset of degenerative disease. The second was the need for the development of a range of accommodation and support options, with Federal and State governments jointly responsible for their requisite funding needs. Concomitant with this was the need for a through review of CSTDA funding arrangements and their efficacy with regard to the YPINH issue.

4 Issues to be addressed

4.1 Inappropriate settings and inadequate services

The problem for younger people in residential aged care is that they are located in inappropriate settings and that there are inadequate services available to address their needs. Yet individual aged care providers are not wholly to blame for either the settings or the services. Their core business is residential aged care, and the difficulty of caring for a single younger person or a small cluster of 2 or 3 in some cases, is enormous and cannot be understated.

Recent years have also seen industry changes in relation to standards, size and composition of facilities that, while advantageous perhaps to the provision of *aged* care, have further intensified the difficulties providers face in supporting the vastly different rehabilitative, emotional, social, intellectual and community access needs of younger residents.
These difficulties include

4.1.1 The significant differences in contemporary disability policy and age care with regard to residential settings and service provision

Contemporary disability policy aims to locate people in their communities and residential services are delivered in settings that do not create institutional environments. Congregate care is limited to units of no more than 5 – 8 people, though even this can fail to provide accommodation adequate to address tenancy rights and individual choice.

Aged care facilities, however, can have 90 or more on a site. Considerations of cost effectiveness within aged care are already seeing sector led moves to embrace even larger settings with concomitantly higher bed capacity ratios. This is something that is set to intensify in the next few years and will reinforce the sense of isolation and loss of identity many young people feel when accommodated with large numbers of older residents.

4.1.2 The vital yet underestimated role of the 'social person' in maintaining overall well being for young people with complex care needs

Social contact with family and friends is crucial to the social and emotional well being of any young person, and is particularly so for YPINH who often live away – both geographically and

emotionally – from their social networks and have limited opportunities to engage socially with others.

Yet nursing homes are not funded to provide the community access that YPINH would benefit from. Their friends find it difficult to maintain relationships with YPINH living in aged care, and friendships tend to fall away and cease with time. Social contact tends to diminish as a result and severe depression and a consequent deterioration in health is the outcome.

Because they live in federally funded and managed accommodation, YPINH have no access to state based disability funds, services or equipment that could facilitate contact with friends and family *away from* the nursing home or a broader program of community access. This and the fact that they are living with older residents generationally removed from them, means that YPINH experience significant social and emotional isolation that adversely impacts their physical and emotional well being. This generational difference is declared in the fact that the majority of permanent residents in aged care nursing homes in June 2001, were aged 75 years or over (85%). Half of these were aged 85 and over and 6% were 95 and over.[5]

4.1.3 The care regime around younger people with complex healthcare and disability support needs is often much more demanding in time and intensity for aged care facility staff

Staffing levels in residential aged care are set to cater for the very different needs of the predominantly frail elderly population these facilities are designed to accommodate. YPINH have diverse and more intensive care needs to those of older residents.

Trying to cater for the more time and energy intensive needs of YPINH places increased pressure on staff and can proportionally reduce the total services and time available for the care of frail older residents.

4.1.4 Many younger people require therapy and equipment services to improve or maintain function

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. Some people in Victoria have access to the ABI Slow to Recover Program that funds rehabilitation to clients with ABI in nursing homes. However, this is exceptional and is not available to the majority of young people with an ABI acquired before 1996 and the start of the ABI Slow To Recover Program, or in aged care with other conditions.

4.1.5 Younger people in aged care facilities are excluded from accessing CSTDA disability services

By virtue of the fact that they are receiving residential care in the aged care sector, YPINH are unable to access CSTDA services, despite being part of the CSTDA target group. Yet the expectation by the CSTDA is that the aged care provider/sector should provide all relevant services required by the young person, including equipment, therapy and attendant care requires.

[5] *Older Australia at a Glance, 3rd Edition, 2004,* Australian Institute of Health and Welfare, Canberra: 82.

The fact is that once a young person enters aged care, they are practically unable to access the rehabilitation they need to recover or improve. Nor are they able to access the equipment or community access services they need. The result is that YPINH are left to languish in aged care facilities when, with the right support, they would have lives of dignity, independence and purpose.

4.2 The Commonwealth State/Territory Disability Agreement (CSTDA

The instrument by which disability services are funded and administered in Australia, the 3rd CSTDA has now been signed off on by the Federal Minister of Family and Community Services and the State and Territory Ministers responsible for disability services. The extended negotiations over the new CSTDA focused, in their later stages, on funding issues in the context of an awareness of unmet need for disability support services and the need for indexation in the light of population growth and service cost increases.[6] The new Agreement was signed in 2003 and will terminate on 30 June 2007.

Younger people with disabilities living in the aged care system are *not* included in this agreement, despite their eligibility for CSTDA services under the various Commonwealth and State Disability Services Acts.

Nor are they part of the group of people identified by the Australian Institute of Health and Welfare as the 'unmet need' group who wait for disability services through the CSTDA.[7] As such YPINH are not considered by the Commonwealth Government in its management planning of the national disability services system.

70 % of people who are receiving services through the CSTDA have an intellectual disability, while over 80% of young people in aged care facilities have an acquired disability. This shows the lack of capacity of the CSTDA sector to plan and provide for people with an acquired disability. We estimate that people with acquired neurological conditions (ABI, stroke, progressive neurological conditions) make up 60 – 80% of young people in nursing homes. In contrast this group is significantly underrepresented in the disability accommodation sector that is dominated by intellectual disability and congenital conditions.

In Victoria specific housing services for this neurological group comprises approximately 1.5% of total expenditure on shared disability supported accommodation.

When comments are made that this group should be absorbed into the disability system, it is clear that this (although administratively attractive) cannot be done without significant service development, because the services they need simply do not exist.

It is apparent that there is a clear lack of strategic planning around future funding arrangements the CSTDA might encompass, and the need for significant increases in disability funding to cope with existing and future unmet need, especially where it arises around YPINH and the rise in disability that accompanies an ageing population.

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[6] See Section 8.5, AIHW 2002b; SPRC 2002.

[7] *Unmet Need for Disability Services: Effectiveness of Funding and Remaining Shortfalls*, AIHW, 2002. http://www.aihw.gov.au/publications/index.cfm?type=detail&id=7741

CSTDA arrangements thus need to make YPINH a priority group and incorporate a 'portability' arrangement whereby disability funds can follow young people with complex care needs into aged care nursing homes and provide for their different support needs while they live there.

As well as facilitating access to equipment, these additional disability funds will allow therapy, recreational and other rehabilitative services to be put into place. They will also allow the increased staffing levels needed to cope with the more intensive needs of YPINH to be instated as well as facilitating the training of aged care staff in disability care.

In short the CSTDA needs to be reviewed to address the increase in demand for disability services now and in the future; and its own efficacy with regard to the ongoing systemic failure that is the YPINH issue, thoroughly reassessed. In this regard, it is clear that the aims of the first CSDA have been comprehensively dismantled and lost.

Anna Yeatman's report on the review of the first CSDA is instructive in this regard.[8] The problems identified in that report remain and have deepened since its publication in 1996. For example, there is still no strategic planning with regard to unmet need and we seem to be going backwards as a result. If strategic planning around unmet need had been done, we might not be confronting the tragedy of the YPINH issue.

The CSTDA also remains extremely vulnerable to party politics. Negotiations are combative in nature and centre on discussions about money rather than strategies needed or service provisions required to meet unmet demand. As one example, the policy of previous Minister for Family and Community Services, Amanda Vanstone, to instate an 80:20 policy wherein the Commonwealth would contribute 20% of funds under the CSTDA to the States/Territories 80%, has never been published.

It is the Alliance's firm view that the CSTDA in its current format needs to either be significantly reworked to confront the growing crisis in demand for disability services; or done away with altogether and a different funding instrument for disability developed to meet the present and future needs of disabled Australians, particularly those young people with complex care needs living in residential aged care.

4.3 Border crossings, Border disputes

The paucity of services in rural areas and the lack of some services altogether in some states, means that YPINH may need to be assessed, treated or accommodated in a different state to their state of residence.[9]

Yet because the cost of service provision in certain sectors is managed by individual states, the latter can be unwilling to pay for YPINH's assessment, rehabilitation, or treatment if this involves doing so in a different state to the state of residence.

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[8] See Yeatman, A. *The Final Report of the Review of the Commonwealth/State Disability Agreement*, Australian Government Publishing Service, Canberra, 1996.

[9] A young Victorian resident suffered extensive injuries in a motor bike accident on private property in NSW. The motor bike involved was unregistered; the child's parents were estranged, one living in NSW the other in Victoria. The Royal Children's Hospital (RCH) in Melbourne was the closest children's hospital and the child was taken there for initial treatment. The RCH was unable to provide the extended rehabilitation and therapy required for recovery and the child was eventually transferred to the Women's and Children's Hospital in Adelaide. Which jurisdiction pays?

As one example, a young man who, until recently, travelled from his nursing home just across the border in NSW to Bendigo in regional Victoria for rehabilitation and assessment services, is now being required to travel to Wagga Wagga to access the same services. This is the result of a dispute between the NSW and Victorian health authorities over who is responsible for paying for these state based services.

The result is that a journey of 1½ hours by ambulance to Bendigo will now take over 6 hours by road to Wagga Wagga. The young man will also have to make the return journey by air ambulance as the long distance traveled is too debilitating for him to make both ways.

4.4 Anomalies in services provided by the Department of Health and Ageing

While the Aged Care Act 1997 accepts people under 65 into the aged care system on compassionate grounds, the large numbers of these people in the aged care system represent an unintended and costly consequence of this compassionate stance. What was always meant as a option of last resort has become the first – and only – line of response for young people with high or complex care needs.

As a consequence, the Department of Health and Ageing is now the largest funder of residential services to people with acquired disabilities (i.e. spinal cord injury, ABI and other neurological conditions) of any government or insurance agency in Australia and the third largest funder of disability accommodation in the country. Yet it remains outside the CSTDA framework. Without DHA's direct involvement in CSTDA discussions and negotiations, this ludicrous situation will continue to confound any moves to resolve the YPINH issue.

With 6,261 people under 65 receiving an average annual RCS subsidy of $38,000 per year, the DHA is expending at least $238m per year on servicing younger residents.

At this point in 2004, this figure represents an $8m increase in costs over the $230m needed to provide for 6,067 YPINH in 2003. Even a conservative estimation indicates that an additional $16m – $20m will be needed *every year* to provide for the rapid growth in numbers of YPINH if nothing is done.

Given the inherent lack of funding growth in the aged care sector, the encroachment of ever more YPINH onto aged care beds will further strain an already highly pressured sector.

When compared with expenditures in other areas of disability, it is clear that DHA's expenditure on YPINH *is already*:

- More than the entire budget for the Disability Services Commission of Western Australia: $204m in 2003/04 for all services
- And approaches 80% of the entire disability accommodation budget in Victoria ($342m in 2003/04)

This massive cost of aged care residential services provided by the DHA to younger people is largely a result of cost shifting by the CSTDA partner agencies. The aged care system is used as a fall back when the CSTDA system cannot respond.

Largely disability pensioners, YPINH take up concessional places and generally do not contribute money via accommodation bonds.

There is a clear need for legislative reform to cope with these anomalies. Either the Aged Care Act itself needs to be reformed to take account of what is now DHA's de facto role in the provision of disability services; or the Aged Care Act needs to be linked more directly with the Disability Discrimination Act as the main Commonwealth legislation covering the rights of people with a disability.

4.5 Level of unmet demand and planning for the future

Faced with an ageing population and an ever increasing – and unmanageable – demand for disability services, significant thought must be given to how future revenue streams for disability and community support will be sustained.

While levels of unmet demand are difficult to quantify, the Australian Institute of Health and Welfare (AIHW) conservatively estimates that there are 12,500 people in need of accommodation and/or respite services in their *Unmet Need Report*. Other industry estimates put this at $400m for accommodation services alone.[10]

Neither of these estimates includes the 6,261 young people currently living in residential aged care, a cohort whose numbers are now increasing rapidly. While the numbers of YPINH nationally were relatively static in 2002, the rate of increase in this current year (2003/04) has risen sharply, and now sees two young people entering aged care every three days. Unless a targeted policy to stem this flow is developed, 10,000 young people will be in residential aged care by 2007.

The Victorian Department of Human Services (DHS) has predicted a 47% increase in demand for funded services in the decade to 2011, and with the ageing of carers and the transfer of unpaid care to paid care, this situation will be replicated in every state across Australia.

The AIHW reports that 24,100 primary carers of a main recipient aged less than 65 years needed assistance but did not receive any; and 39,200 needed more assistance than they currently received. 77,900 did not have a fall-back carer.

4.6 The Hogan Review into Aged Care

In the recent Hogan review, it was noted that the YPINH problem was significant, and a poor outcome for all stakeholders.

> The needs of the younger disabled residents are not being met as fully as they might be if they were accommodated somewhere more suitable. Provider resources are being stretched and the Australian Government is funding residential aged care beds which are not being occupied by the target population, that is, the frail aged… The Review notes that one of the priority areas for action in the third disability agreement is the intersection between the ageing and disability support systems, particularly for people with a disability who have age care–related needs, and younger

[10] AIHW, Unmet Need for Disability Services: Effectiveness of Funding and Remaining Shortfalls, No. 22, September 2002.

> people with a disability living in, or at risk of living in, residential aged care…The Review considers that no disabled person should be disadvantaged as a result of their residential status in an aged care facility.[11]

The Review supported an audit of younger people in nursing homes "…to measure the number, characteristics, age, disability types, assessed care and support needs, and geographical location of younger people with disabilities living in residential aged care."[12]

The National Alliance is skeptical about an audit taking place and creating delay in the onset of deliberate and urgently needed action. A range of models already exists that can be replicated; more of the same types of models is needed. In this regard, see *Table 4 Existing models of accommodation for the YPINH target group and comparative funding levels.*

Table 4 Existing models of accommodation for the YPINH target group and comparative funding levels

Model	Funding Body	Approximate Annual funding	Client group
Younger person's cottage annexe on an aged care campus, providing 24 hour nursing care model with mix of nursing and trained PCA 12 residents	CTP insurer Private Compensation	$ 73,000 per resident	Complex ABI
Accredited nursing home with a younger person's section 24 hour nursing 15 residents	Dept Health/Ageing Dept Human Services	RCS 1&2 $236,000 $54,700-$58,700 per resident	Multiple Sclerosis
Disability specific group home staffed 24 hour with PCA + nursing + therapy and community access 6 residents	State Govt Disability Services	$80,000 per resident	Degenerative neurological conditions
Disability specific units providing 24 hr PCA staff cover to 6 people with ABI. 2 of the group have come from nursing homes in 2002 to this service 6 residents	State Govt Disability Services	$56,500 per resident	People with ABI (moderate high needs)
Regular aged care nursing home Up to 90 residents or more	Department of Health and Ageing	Up to $43,000 p/a for RCS 1	Frail aged people and younger people with disabilities

[11] Investing in Australia's Aged Care, Review of Pricing Arrangements in Residential Aged Care, Department of Health and Ageing, 2004: s 13.2.3.
[12] Ibid.

If such an audit *is* seen to be necessary, it should be incorporated into a National YPINH Project that is adequately mandated and resourced to be able to action the provision of alternative services to those young people who indicate their desire to move out of their inappropriate nursing home accommodation. Merely asking people who they are and what they want is not sufficient.

Adequate research data exists on the need to get YPINH out of aged care. While we certainly need to consult *with* them, we do not need to merely count them.

4.7 Limitations of the Aged Care Act and the need for legislative reform

Entry into the aged care system for young people is via the Aged Care Assessment Service and a policy determining that people under 65 are eligible to enter the aged care system. Beyond this statement and assessment process, the entire Act and DHA policy frameworks are silent on the particular expectations and care regime needed for young people.

Because the Aged Care Act is prescriptive, things that are not stated in the Act are not acted upon. Both the standards, provider approvals, policies, practices and workforce management, will ignore many of the needs of young people who can spend over 40 years in the aged care system.

The fact that these young people are in aged care due to the failure of the CSTDA jurisdictions and other systems, does not mean the Commonwealth should ignore them in the Aged Care legislation. Failing to give due recognition to genuine need will not suppress its existence. The particular lack of recognition of young people by the Aged Care system and its Act has not of itself encouraged or forced the CSTDA sector to accept a greater share of responsibility.

Disability Services Legislation is, by contrast, enabling legislation and does not contain clear definitions about entitlement, processes, access to services or the reach of services.

Because this is outside their mandate under the current arrangements, it is unrealistic to expect Aged Care providers to provide anything like a disability service to a young resident, or to be able to actively assist someone to move out. Indeed, where a young resident wants to acquire independence skills and undertake activities like cooking or going out alone in their wheelchair, it may even put their accreditation at risk. In the course of meeting their obligations – and generally without malice – they can, however, effectively ignore many of the needs of young residents.

It has become a practical reality that younger people will continue to reside in residential aged care facilities because of demand issues in State Disability Services, pressures on acute care beds, geographical considerations and the sheer force of timing demands between the competing interests of health and disability.

These practical contingencies mean that the Aged Care Act needs to be modified to accept that a significant number of its target group are poorly served by its current scope and are, in many cases, being damaged by its implementation. It may be the job of CSTDA jurisdictions to provide accommodation services, but they simply cannot absorb this YPINH group under current arrangements leaving this vulnerable and needy group to remain as a ‘fixture’ in the system.

Aged care is often the overflow safety net for the community in regard to unmet need for accommodation services. Aged care has become *the* de facto disability accommodation provider over the years and a reluctant and ill-equipped one at that. If this is a direction it is willing to accept, then a dedicated section needs to be created in the Aged Care Act to ensure adequate care is funded and provided; and that aged care standards reflect this role.

If aged care is to maintain its role and its integrity as the sector that cares for the aged, then a targeted program to remove YPINH from aged care *and* establish policy and practice to prevent entry of younger people in the future, is required. This is a complex task and involves looking beyond the borders of aged care and disability.

A funding source for disability that is impervious to political whims is clearly – and urgently – needed.

Given this, the Commonwealth has a responsibility to provide increased service levels and targeted standards through the Act for this group.

Yet, as things presently stand and apart from the Commonwealth Innovative Pool, the only other high level action is with the National Disability Administrators (NDA) of the CSTDA. This group now has YPINH on their current work plan. While this is a good start and will bring YPINH into their planning, it is unrealistic to expect that a group of disability bureaucrats will be able to secure additional resources and make any meaningful change in the absence of legislative backup and reform. A group such as this will always struggle to influence Aged Care legislation and impose the enabling provisions of their own disability legislation on the Department of Health and Ageing who are not part of the NDA. In any case, the NDA would say that it is not their job, though it is a job that needs to be done.

The impetus and mandate for change in this area lies fundamentally with the Commonwealth giving strong legislative and political guidance. Clearly, real change must come from Government, not the administrators. The link between legislation, administration and the community in this area needs to be clearly articulated through a revision and articulation of the Aged Care Act and the CSTDA framework.

4.8 Nursing Homes as Transitional Services

The imperative to tackling this problem in the current climate of aged care reform, is to cast aged care facilities as transitional facilities for people under 65, and not try to make a young person fit the aged care model for life.

This requires a number of changes to the current system, centering on the closer integration of the aged care and disability systems to enable better movement and availability of appropriate options for people.

The National Alliance supports the establishment of a National YPINH Project with a target to re-house an agreed number of young people over a 3 year period, similar to the one that was carried out in WA in the second CSDA.[13]

[13] Jones, G & Lawn, R. The History of the YPINH Project from 1995-1997. Report One of the Young People In Nursing Homes Project Evaluation; The Efficiency and Effectiveness of the Project Teams and Project Management Structures. Report Two of

We also support a review of relevant jurisdictions (Home And Community Care (HACC), Aged Care, Disability and acute care) to identify and integrate their operation to minimise the number of young people living in aged care. The Community Care Review begun by the Commonwealth some years ago may be the place to carry this out.

4.9 Systemic Discrimination

YPINH have been discriminated against on the basis of age and disability on a number of levels.

If such provisions as s.69 of the *Equal Opportunity Act 1995* (Victoria) were not a bar to such action, an individual or a number of complainants may have a claim for discrimination under the *Equal Opportunity Act* (and also under the *Disability Discrimination Act 1992* (Cth), notwithstanding s.14(2)) against:

- a particular nursing home, in respect of the services provided to the complainant(s); or
- against the Victorian Government, both for failing to provide YPINH with the services that they are entitled to under the *Disability Services Act* and the CSTDA; and in respect of the different regimes administered by the Government for those with intellectual disabilities

The bind that young people in nursing homes find themselves in is that there is no formal avenue for redress of their plight:

- The Aged Care Complaints system is only able to deal with issues directly related to the Aged Care Act 1997 and the quality of care principles and standards, so cannot resolve a complaint about a problem that is outside this ambit (although the Commissioner for Complaints has referred to the need for the Commonwealth to pursue with the States ad Territories
- Anti Discrimination legislation provides no real avenue for redress as provisions in the Disability Discrimination Act (1992) and State Equal Opportunity Acts are very narrowly defined, and do not allow for comparisons between 2 groups that share the same attribute (i.e disability).
- The Commonwealth State Disability Agreement is an administrative instrument with no direct complaint mechanism for a person with a disability. Ironically, the national disability standards the Disability Services Acts include the requirement for an accessible grievance procedure, however it is only accessible if you are a client of a service, making YPINH unable to use such processes

Discrimination against YPINH occurs at a systemic level, which is something that the narrow provisions of the legislation are not able deal with. The situation must thus be dealt with pro-actively by the state government, who is responsible for the provision of disability services, and not tackled in an ad hoc fashion through the anti-discrimination system.

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the Young People In Nursing Homes Project Evaluation; Evaluation of the Individual Planning Process. Report Three of the Young People In Nursing Homes Project Evaluation, Perth, Western Australia: Disability Services Commission of Western Australia, 1999.

As a result, it is necessary to amend the *Disability Services Act* and the *Equal Opportunity Act*in order to attempt to remedy the inappropriate circumstances in which YPINH find themselves. Legislative changes must ensure that whoever provides services cannot ignore young people with physical and sensory disabilities, regardless of how they are funded. The Victorian Government clearly recognises the shortcomings of the existing legislation, as it is currently undertaking a general review of disability legislation, although this is not from a purely anti-discrimination perspective.

The existing *Disability Services Act* can itself be considered discriminatory because it fails to deal with the systemic discrimination affecting YPINH. That an act dealing with the provision of disability services can fail to address disadvantage on the basis of disability or age in institutions, implying, through its subsidiary agreements, that its responsibility ends when disabled people are placed into nursing homes, is clearly unacceptable and discriminatory.

The *Act* must be amended to *require* the consideration of non-discrimination in the provision of services, or at least an obligation to consider the needs of all parties concerned. This would be achieved by the inclusion of an enforcement mechanism, to ensure that the general principles and objects detailed in the schedules to the Act are carried out. Although it appears that, prima facie, s.109 issues of inconsistency arise, these need not be a problem: although the Commonwealth Government funds nursing homes, the Victorian Government retains legislative power over the provision of disability services.

In addition, amendments to the *Disability Services Act* are also necessary to ensure that equal access to a range of housing and support service options is available to people with physical and sensory disabilities, irrespective of age. The creation of these new services may require the state government to negotiate with the commonwealth government to obtain extra funding. It is also necessary to amend the *Aged Care Act* so that it takes into account the requirements of those people not commonly accommodated in the aged care system.

If s.69 of the *Equal Opportunity Act 1995* (Vic) and s.14(2) of the *Disability Discrimination Act 1992* (Cth) were not a bar to such action, young people in nursing homes may have a claim for discrimination under both of these Acts against both specific aged care nursing homes and against the Victorian Government in respect of services provided, although it is unlikely that such claims would ultimately succeed.[14]

4.10 Reform of personal injury insurance arrangements

The role of insurance in adversely impacting the CSTDA's potential to provide the disability services is one that has received comparatively little attention. Yet the AIHW has, amongst other groups, identified insurance as a major factor in revenue and demand pressures on government. In its *Disability Data Briefing No. 22*, the AIHW says

> **Insurance** has a triple possible impact on the CSDA program. People excluded from benefits (because of the fault aspects of insurance) create pressures for government schemes (the Disability Support Pension as well as the CSDA). Insurance costs are said to be impacting on the financial viability of Non-government organisations and the

[14] See Pryles, S. Submission to the Victorian Scrutiny of Acts and Regulations Committee, July 2004

> resources available for support services. And insurers can be reluctant to insure some high support needs and 'dangerous' clients.[15]

Acquiring a non compensable injury or contracting a disease such as Multiple Sclerosis or Muscular Dystrophy, is a pathway almost guaranteed to circumnavigate disability funding and take you straight to aged care. As present arrangements stand, the resulting circumstance is one on which the individual will be forced to rely but without being able to access support from any of the personal injury schemes into which we pay premiums. The result is that individuals who acquire non compensable disabilities dutifully pay, together with their families, premiums for these schemes at great cost. Yet they are unable to derive any benefit from them.

Forced to rely on unpaid family care or end up in nursing homes to receive their care, this situations is a direct result of the fact that we as a community insure for the cause of injury rather than the effect. Quite apart from their inherent inequity, the increase in demand for community care and the rising cost of healthcare makes the level of duplication across these schemes untenable.

4.11 Jurisdictional fragmentation

The landscape for support of people with disabilities is renowned for its fragmentation. When personal injury schemes are added to the equation, the jurisdictional confusion gets worse.

> Australia's social welfare system is funded and delivered at the federal level while existing workers and transport accident compensation schemes are funded and delivered at the state level. Both levels carry conflicting cost implications and sustain limited recognition of the supportive benefits delivered by the other.
>
> The establishment of a scheme to provide long term care for the most seriously injured would provide an opportunity to examine the interaction of the various bodies whose funds become the primary support mechanism for potential clients. While the interface between costs and benefits is particularly significant, it is also important to identify other areas in which funding is potentially duplicated, and which could be unlocked and better utilised in a long term care scheme by providing a coordinated and integrated system.[16]

To ensure adequate 24 hour care for a person with a catastrophic disability that includes physical and cognitive support needs, a lump sum payout of at least $2.5m needs to set aside. When equipment needs, therapy, healthcare, home modifications and attendant acre are added, it is clear that significant sums are needed if support is to be maintained over the lifespan.

Based on the narrowness of their premium base and the pricing requirements of each scheme, the premium cost of each of these schemes does not reflect the real risk. The most obvious example of this is the comparison of medical indemnity premiums where the professional is insured with premiums up to $100,000 per doctor, to the Transport Accident Commission (TAC) in Victoria where the premium is less than $500 per vehicle yet covers not only every citizen of that state *as well as any (non Victorian) driver/passenger in a Victorian registered vehicle*.

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[15] Unmet Need for Disability Services: Effectiveness of Funding and Remaining Shortfalls, Disability Data Briefing No. 22, September 2002: http://www.aihw.gov.au/publications/dis/ddb22/ddb22-c13.html

[16] Walsh et.al *Options and issues for Long term care in Accident compensation*, Institute of Actuaries of Australia LTC Task Force, 2002.

The risk of catastrophic injury on the roads is statistically far greater than that on the operating table. Yet the structure of the scheme and the capacity to pay determines the cost. And because medical indemnity premium costs are passed on to consumers and our taxes continue to prop up clearly unviable funds we, as citizens, pay either way.

To secure the $300m that is required to solve the YPINH situation for the 6261 young people currently resident in aged care facilities, just 64 cents per week from each of this country's 9 million taxpayers is required. This comparatively small amount – a mere 4% of the Federal budget surplus – would free up aged care beds *and* hospital beds, and return $372m worth of precious health dollars to the sick.

Yet the net dollar gain and the systemic relief that could have been achieved was once again passed over in favour of a $4.00 per week personal tax cut from the Commonwealth in October 2003, and the problems continue to intensify.

A case in point is that of Laura Brown. Laura was just 12 years old when she fell into the shallow end of a swimming pool while competing in a swimming club competition. Now 16, Laura is a quadriplegic, unable to walk, stand, shower or dress herself or roll over in bed. She has no control of her bladder or bowels and is dependent on carers to perform the most basic tasks. As a year 10 student, Laura struggles to keep up with her classmates. She requires an aide to take notes for her and has frequent absences due to medical problems.

A keen dancer, netballer and horserider before the accident who trained several nights a week with the swimming club, her loss of independence has forced Laura's family to move to Melbourne for Laura's medical treatment. In a case currently before the Supreme Court of Victporia, her parents are suing the Swimming Club for millions, claiming compensation for pain and suffering, for the cost of providing equipment, treatment and attendant care and for loss of income.[17]

Laura Brown pictured with her mother, Robyn, outside the Supreme Court. Picture: *Michael Rayner*

When you consider that each state has its own separate schemes for transport accidents and work accidents; its own health department that is funded by the taxpayer who also picks up the tab for private health insurance and medical indemnity schemes, Australians are grossly overinsured with more than 30 individual schemes they can contribute to.

Clearly, our population cannot continue to support this duplication.

In the same way that federal/state views on wars or border protection can lead to policy disputes, the growth of demand for disability and aged care has also resulted in feuds between the Commonwealth and the States, particularly around the CSTDA (re)negotiations. With the community's need for care increasing and the funding to provide this care remaining static, maintaining this historically dichotomous situation will only intensify an already desperate state of affairs and do nothing to solve the YPINH 'problem'.

[17] Topfield, J. "Parents sue after child's pool tragedy" *The Age,* August 3 2004, http://www.theage.com.au/articles/2004/08/02/1091432113491.html

A national no fault insurance scheme that would operate in a similar manner to that of the TAC in Victoria, is an essential element in any effort to solve the systemic problems that have brought the YPINH issue about. The establishment of such a scheme has already received support by the Productivity Commission in its recent *Report into National Worker's Compensation and Occupational health and Safety Frameworks:*

> **Care for the catastrophically injured**
> In workers' compensation schemes, the catastrophically injured account for a small proportion of claims but a larger proportion of scheme costs. Claims relating to such events can have a significant impact on employers and on the financial performance of those schemes that do not shift a proportion of these costs to the Australian Government. There is wide community concern about the care of catastrophically injured persons and it has been the subject of discussion at Ministerial meetings on insurance issues.

With the majority of catastrophic injuries – some 61 per cent – resulting from motor vehicle accidents and workplace accidents contributing a further 13 per cent, the cost of caring for catastrophically injured persons varies considerably and depends on injuries sustained. Invariably it is large.

The funding available from insurance depends on the cause of the injury and its adequacy for meeting the cost of caring varies considerably. Most cases eventually involve Australian Government funding. The Commission considers that a national approach could ensure that an appropriate standard of care is provided to the catastrophically injured, irrespective of cause of accident, and supports a review to this end. [18]

Support for such a scheme is growing across the Australian community and indeed has the support of some state governments and the AMA. The Prime Minister has also expressed a desire to move down this path as demonstrated in the following excerpt from Hockey's press release.

Following the collapse of the HIH insurance group in 2001, the then Minister for Financial Services and Regulation, Joe Hockey, said in a press release that

> The Prime Minister will write to Premiers and Chief Ministers seeking their co-operation undertake a thorough review of State and Territory regulation, with a view to introducing national insurance schemes in Compulsory Third Party, Workers Compensation and Builders Warranty insurance, as well as putting in place a national approach to flood insurance.[19]

The Alliance wonders what has become of this move.

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[18] *National Worker's Compensation and Occupational Health and Safety frameworks*, Productivity Commission Inquiry Report, No. 27, 6 March 2004: XXVIII – XLIII.

[19] See Appendix A: *Government Action to Help HIH Policyholders*, Press Release, Minister for Financial Services and Regulation, the Hon. Joe Hockey, dated 14 May 2001.

4.12 Lack of National Leadership

The leadership call from the *2002 National Summit on Young People in Nursing Homes* has effectively been taken up nationally by DHA in the absence of any action or leadership being shown by the Department of Family and Community Services in their role in the CSTDA.

The Alliance congratulates the initiative taken by the DHA in making the Disability/Aged Care interface a priority area in the 2002/03 Innovative Pool Program and in making the YPINH issue the focus of the 2003/2004 Innovative Pool. Steps like this need to be taken by DHA to strengthen and protect its own system in regard to CSTDA cost shifting.

The Alliance is keen to see further partnership approaches to the development of sustainable accommodation and support options for young people with complex care needs between the Commonwealth and the States/Territories.

4.13 Experience of Aged Care Providers

It is the experience of the National Alliance (and the Victorian Consortium as its role as Alliance Secretariat) that most aged care providers with younger residents go out of their way to provide a good service. As well as the financial and operational difficulties for providers, the presence of younger residents takes an emotional toll on staff.

Providers are well aware of the inadequacy of their environments and the limitations of their resources in meeting the needs of younger residents. It is not their core business.

Reports from providers and first hand experience of young residents and their families highlight the inappropriateness of the service available in aged care facilities due to the fact that the funding subsidy arrangements meant to serve the more limited needs of the frail aged, are applied to the more extensive needs of younger people in the same way as the frail elderly.

Many of these younger people have complex care needs that even the disability system finds difficult to manage (due to their nursing needs), so their presence in an aged care facility puts great stress on the care service and the capacity of residential staff.

The National Alliance is aware of a number of providers that, having taken one younger person on compassionate grounds, would not take another one due to the high cost and operational demands involved.

This is particularly true of people with a degenerative condition such as Multiple Sclerosis or Muscular Dystrophy where support needs increase markedly over time, or for people with high physical or cognitive support needs associated with acquired brain injury.

These providers have accepted the challenge of managing younger people trying to engage again in an environment where aged people are letting go of life. The measure of vigilance of families and staff to maintain high standards of care in the constrained environment cannot be underestimated.

The needs of a person cannot be made to fit a funding model, and their complex health and disability support needs have to be met in whichever environment they are in.

4.14 Improved staffing levels, training and resourcing for Nursing Home staff

While younger people in aged care have unmet need in the areas of therapy, equipment and recreation, their support needs must be met with immediacy in a facility, and this draws heavily on available staff and the total resources of the provider.

Where younger residents have severe cognitive impairment resulting in behaviour that is difficult to manage in the setting, staff, management and other residents are put under extreme pressure, and there are often no outside resources to assist, other than brief secondary consultancy services.

Providers have spoken about the features of younger people that place additional demands on their resources:

- being physically bigger and stronger, requiring more staff to transfer and task care
- managing challenging behaviour
- managing acute boredom and depression
- PEG tube and catheter care
- pressure care routines
- therapy and equipment requirements
- recreation and social needs beyond those traditionally being provided for older residents (often recreation staff are required to do 1:1 activities with young residents
- specific staff training requirements

There is a clear need for specialised training and resourcing to cater for the very different needs and expectations of young people with high or complex care needs.

4.15 Funding issues

Residential care subsidies do not take the additional needs of younger people into account. Indeed the ACAS system itself and the assessment tool used is not appropriate to measure the funding required by providers to meet the needs of individual younger residents, nor is it adequate to provide an assessment of the needs of young residents or any sense of their life goals.

Funding levels for people in this group in other jurisdictions can be between $75,000 - $90,000 per annum in the non government sector for the provision of a residential service in more appropriate community scale settings, while aged care receives a maximum of $43,000 RCS subsidy level.

The Productivity Commission's *Report on Government Services 2003*, shows that in some states the cost per head for a disability service can be as much as $107,000 per annum. Some non-

government services can receive as little at $46,000 per annum. However these services are ones that do not operate on a 24 hour a day staffing model.[20]

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. While there is limited experience with this group in the CSTDA sector, there are some very good service models are available. What is missing is recognition of realistic funding for this group in the CSTDA itself.

The current subsidy arrangements cannot meet their needs without substantial cross subsidisation of care resources from other residents in the same facility. Providers that were approached by the Alliance for data on the extent of cross subsidisation were unwilling to provide information because of potential recriminations from families, residents or the Department. They did, however comment that it was a real problem.

4.16 Comparative funding

The following comparison takes a person who has 24 hour per day care needs, and shows how they may be funded if they are fully serviced by Disability Services. (This does not take into account many of the costs that are reported by the Productivity Commission 2003).

This is compared with a person with similar 24 hour care needs and the funding they can attract to meet those needs in the aged care sector. Placement in aged care does not represent a government saving: need is just not being directly met. Some of the unfunded need of these young residents in aged care facilities is met through cross subsidy from other residents. Other need simply goes unmet, resulting in poor lifestyles that are anathema to those sought by the disability and aged care standards.

Table 3 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

* NB The difference represented above does not represent a dollar saving but represents unmet need.

[20] Productivity Commission Report on Government Services, 2003: 41-47
http://www.pc.gov.au/gsp/2003/attachment13revised.pdf

5 Recommendations

The *National Alliance* is working with the Aged Care industry, Federal and State governments and YPINH and their families to find sustainable solutions to this long standing problem.

As previously indicated in this submission, the YPINH issue is a problem of inadequate services and inappropriate settings that centre on a group of younger residents who should have their complex care needs met through the CSTDA. Their presence in aged care challenges providers and places pressure on the system. It is not acceptable for the CSTDA sector to expect Aged Care to continue to fill the service gap without taking action itself to address this need.

The YPINH issue is also emblematic of a wider systemic failure around service provision and unmet demand. It will clearly take more than the repricing of aged care services to resolve the issue for both younger residents and providers alike. However, the capacity to recognise younger residents and their needs through comprehensive assessment and appropriate funding remains a critical developmental issue in the short term.

To solve the tragedy that is the Young People In Nursing Homes issue, it is essential that we move away from the cost shifting imperative that has characterized responses for the last 30 plus years. It is also vital that disability funding follows young people into nursing homes, whether they move there as a transitional option or choose to remain as one of the accommodation and support 'options on the spectrum' made available to them.

To action this, the CSTDA must be abandoned as a single agreement and other Commonwealth States/Territories agreements like Housing and Health, be mandated to include Disability. In this vein, partnership agreements like the Home and Community Care (HACC) arrangements that exist between the Commonwealth and the States could be developed, but without the complexities inherent in current arrangements. This would minimize cost shifting and make funds and services available to the people who need them as they require them.

To that end, the *National Alliance of Young People In Nursing Homes* recommends that the following actions be implemented immediately:

5.1 The development of a specific assessment and funding mechanism for younger people with high/complex care needs, to be added to the current scale of subsidies. Such a mechanism would act to prevent this cohort moving into residential aged care; sustain YPINH while they live in aged care facilities; and assist them to take up one of the accommodation and support 'options on the spectrum' available to support moves into community based living arrangements.

The momentum around unmet demand is now so great that young people with high or complex care needs often leap completely over Disability assessments and go straight to Aged Care Nursing Homes. This 'express train' approach to unmet need is part of a crisis response model that characterizes reactions to this problem, rather than much needed forward planning and actions.

Instating a specific assessment and funding mechanism would short-circuit the existing "expressway" to Nursing Homes and allow for more considered and appropriate responses to be

made. Something like a "Super ACAS Team", comprised of a range of disability specialists, could constitute such a mechanism that assesses and recommends further action in consultation with young people and their family members. The Commonwealth would jointly administer this new arrangement with the States/Territories to ensure both jurisdictions meet their obligations to individual residents.

5.2 The development of an improved assessment tool that can link realistic funding levels to the needs of younger residents with complex needs.

Such an assessment tool needs to go beyond the physical needs of young people with high/complex care needs, and include considerations of needs like 'the social being', as well as emotional, intellectual and rehabilitative requirements.[21]

Some work has begun on the development of such a tool. But the difficulty around privacy issues and the consequent need to first *find* YPINH before assessments can be undertaken, makes progress slower than is desirable. If YPINH are to receive the supports necessary to have lives of dignity and meaning, however, the development of such an assessment tool is imperative.

5.3 Department of Health and Ageing (DHA) becomes a signatory to the CSTDA.

Because of the size of the Department of Health and Ageing's contribution to the accommodation of young people with high support needs from acquired disabilities, DHA should move immediately to become a third signatory to the current agreement and to subsequent Commonwealth State/Territory Disability Agreements. This will enable the current cost shifting practices by existing CSTDA signatories to be managed across jurisdictions with greater transparency.

5.4 That DHA negotiate with the CSTDA parties to ensure appropriate and timely access to funded disability services by providers and younger residents.

As this submission has indicated, the lack of access to appropriate rehabilitation, community access and other support services can adversely impact the well-being of YPINH by reinforcing senses of isolation and social dislocation.

It can also reduce the chances of recovery for many younger residents who might otherwise have an improved chance of becoming a productive member of their community again.

Because of their potential for successful rehabilitation, access to these services carries the possibility of significant reduction of costs associated with the support of a young person with high or complex care needs over the longer term. Advances in medical technologies and health care mean that some young people with high/complex care needs who may not have been able to return to their communities and engage in study or work related activities (paid or unpaid), may be able to do so now

5.5 That the Commonwealth and the States/Territories agree to a National Exit Project to bring 700 YPINH out of Nursing Homes every year into community based living

[21] See Kendrick, M. "When People Matter More Than Systems", Keynote Presentation for *The Promise Of Opportunity Conference*, Albany, NY, March 27-28, 2000.
http://www.socialrolevalorization.com/resource/MK_Articles/NYConferencePresentation.pdf

arrangements, while at the same time providing improved accommodation and support strategies to prevent others entering, and enable access to disability funds for those waiting to move into the community.

YPINH are amongst the most vulnerable members of our society with some unable to speak and advocate for themselves. A *National Exit Project* involving the Aged Care and Disability sectors is needed to make sure these young Australians are not forgotten in their desires to return to community living arrangements.

Such a project also needs a legislative response to ensure that the practical provisions of the Aged Care Act are married with the policy directions of Disability. In other words, the answer to this dilemma lies not in a purely policy driven response but in policy underpinned by appropriate legislative reform. Unless this is achieved, the best policy in the world will not ensure adequate care and humane support for young people with complex care needs.

Providing a range of accommodation and support options for YPINH is achievable, necessary, and cost effective. Assuming an average cost of $70,000 for each young person with high/complex care needs – some YPINH may require more dollars, some will require less – offering alternative accommodation and support options to 700 YPINH each year would cost on average $49m per year (70,000 x 700 = $49m). This is a tiny fraction of the $372m that is already spent annually to keep 2,500 frail older Australians in acute care hospital beds because the aged care beds they need are not available. As well as freeing 700 aged care places, a further consequence of this action is that moving 700 frail elderly folk into aged care beds will result in an annual average saving of $104,160,000 to health budgets nationwide (148,800 x 700 = $104,160,000)

The advantage of a *National Exit Project* is that it would carry a strategic impetus to service development on a national scale. If service development is not made part of such a National Project, there is a real risk that the States and Territories will not create new accommodation and support options.

As an example, since the development of its State Disability Plan in 2001/2002, Victoria has done little to reduce numbers of YPINH and currently leads the nation in admissions of young people to aged care facilities. While Victoria intends well, its bureaucracy cannot deliver. Similarly, Western Australia's efforts to bring its then **population of** YPINH into community based living arrangements did nothing to address unmet demand and service development. As a result, there were no provisions in place to prevent the next wave of young people with high/complex care needs going into residential aged care.

Given Australia's ageing population and the increase in demand for disability services this will bring, the importance of a national service development strategy cannot be underestimated. What will happen when ageing carers can no longer provide this service?

Already struggling to address the needs of its primary client group Aged Care, as the default service system for young people with high/complex care needs, is unable to address this projected increase in demand. This situation will worsen with the ageing of Australia's population and gives added credence to efforts to move YPINH into community based living arrangements that will free up the aged care beds these young people currently occupy.

5.6 That a range of sustainable accommodation and support options be developed in consultation with YPINH and their families as well as members of all stakeholder groups.

There is no one solution to this complex issue and a range of accommodation and support 'options on the spectrum' need to be made available to young people with high/complex care needs.

Previous systemic efforts to find/develop models have necessarily focused on data gathering and assessment, but to such a degree that action has become bogged down in this assessment phase.

Despite this, a number of successful options already exist and have come about almost despite the (bureaucratic) desire for studies to be completed before action is taken. These include

a. Cyrill Jewell House, Melbourne: a dedicated 15 bed younger person's annexe attached to an aged care nursing home. Designed for young people with MS, CJH receives funding from both the Commonwealth and the State to provide the support these young people need.
b. Blackwood Street, Carnegie: a 3 person shared supported accommodation house in suburban Melbourne that has brought 3 young women out of nursing homes through the Innovative Pool Program. The Federal and Victorian State governments jointly fund this house.
c. St Martin's Court, Beaumaris: a former aged care hostel site that contains 10 individual units. Residents pool attendant care hours to maintain on site attendant care 24/7. St Martin's Court is slated to open on August 10, 2004.

Each of these examples is established and operated within parameters that vary according to the assessed needs and expressed preferences of residents, and the different funding formulas used to support the venture.

These three examples alone show that additional research or pilot studies around 'best practice' and 'best models' is unnecessary. What *is* needed is a commitment to consult with YPINH and family members around the options best suited to their declared needs and imperatives. For a full list of available options, see Table 4, page 14 of this submission.

As well as these diverse choices, the Alliance firmly believes that maintaining nursing homes as one option on the spectrum is important for several reasons. Some YPINH may not wish to move out of a nursing home if the facility is geographically close to social networks of family and friends. This is especially important in rural areas where critical mass may be low and services more limited. Where a YPINH chooses to remain in a nursing home, the requisite disability funds to support rehabilitation, equipment and community access services amongst others, *must be made available* to provide a life worth living for that young person in residential aged care.

Nursing Homes will also remain a first line of response for moves from acute care to less intensive support, especially where alternative accommodation and support choices are not immediately available for a young person with complex care needs. As a 'transitional option', disability funds will need to follow young people into these facilities to provide the rehabilitation

and support services they need while waiting for community living arrangements to be made available.

Australia's ageing population and the rise in disability that accompanies age also means that the previously sharp divisions between aged care and disability will become increasingly blurred.

5.7 Consult directly with YPINH and family members.

It seems axiomatic to insist that YPINH and their family members be consulted in determining support needs and where and how a young person wants to live. Yet because the crisis in accommodation and support for these young people is so acute, such consultations rarely take place.

Within certain limits, YPINH and their families know what they want better than anyone. They should and need to be involved in the process of decision making around their accommodation and support needs. This involvement needs to be ongoing and be able to take account of life changes and other variations in support and accommodation requirements.

5.8 Mandate aged care providers to manage the annual health check to ensure young people with complex care needs have their health needs met.

Recent Medicare changes have instated an annual health check for every resident of an aged care nursing home. Paid for by Medicare, this health check should form the basis for more intensive review that would be contributed to by the Disability sector and which would examine existing and unmet need, quality of care, establish YPINH's life goals and update progress on the achievement of these, evaluate and ensure community access for YPINH and so on. As part of the Commonwealth's response to the YPINH problem, Aged Care service providers should be mandated to ensure that YPINH have their health needs regularly assessed and met through this measure.

These changes to Medicare also ensure that, from July 1 2004, aged care facility residents have access to five allied health service sessions per year. Through an Enhanced Primary Care Plan created by a GP, a range of allied health services can be obtained, including occupational therapy, dietetics, psychology, speech therapy, podiatry and chiropractic and osteopathy services.

Ideally, the Super ACAS team attending with a doctor to complete the annual medical check, could also carry out a more intensive assessment and develop an enhanced Primary Care Plan for access to these Allied Health services**.**

5.9 Count YPINH in assessments of unmet need

At present, YPINH are not counted in calculations of unmet need. If accurate forward planning is to be achieved around service provision in disability, this cohort of young people with high and complex care needs must be included.

5.10 Alternative Funding Structures

Different states have significantly different numbers of nursing home residents who have ended up in this predicament because of poor or limited compensation such as that available under the

Victim of Crimes Compensation Program in Victoria; the existence of fault based insurance scheme's such as the schemes operant in Queensland and Western Australia; or because no compensation is available as in cases of degenerative neurological diseases.

The need for a national no fault insurance scheme is nowhere declared more starkly than by the Young People In Nursing Homes issue. The establishment of such a scheme has already received support by the Productivity Commission in its recent *Report into National Worker's Compensation and Occupational health and Safety Frameworks.*[22]

5.11 Radical overhaul or dismantling of the CSTDA

Given the protracted debate and the political overlay that accrues around CSTDA negotiations, as well as the relentless demand for disability supportive services, the CSTDA as currently constituted is functionally unworkable. It needs to either be radical overhauled or dismantled altogether and replaced by a funding instrument that incorporates a partnership approach to service provision bwteen the Commonwealth and the States.

5.12 Legislative change

The Aged Care Act 1997 must be changed to incorporate the specific needs of the growing number of young people who come within its jurisdictional purview.

[22] *Report into National Worker's Compensation and Occupational health and Safety Frameworks,* Australian Productivity Commission Inquiry Report, No. 27, 6 March 2004: XXVIII - XLIII

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7 Appendices

7.1 Ministers edge forward on no fault insurance plan (separate pdf file)

7.2 Joe Hockey press release (separate pdf file)

7.3 Case Studies of young people living in residential aged care

7.4 Call to Action, National Summit on Young People In Nursing Homes, May 2002

Appendix 6.3
Case studies of young people living in residential aged care

Jack
The victim of a misdiagnosed meningitis attack, Jack became unconscious, vomited and suffered a hypoxic brain injury as a result of aspiration. He was 24.

His parents were told he would not revive from coma and advised to turn off his life support. They refused and were subsequently told Jack would remain in a persistent vegetative state for the rest of his life.

While still coming out of his coma, Jack was sent to an aged care facility. To this day, 9 months post-injury, Jack has not received one minute of rehabilitation or specialist support other than minimal stimulation and stretching of his limbs that his parents have managed to provide themselves. He has no equipment and needs, amongst other items, a wheelchair and tilt table to continue his recovery.

Despite this, Jack has made a remarkable recovery. Now 25, he is speaking, moving and eating again, progress that is due entirely to the efforts of his parents who have had to develop a rehabilitation program by themselves. They are not medicos. Jack's father is now in danger of losing his job because of the time he has had to take to attend to Jack's recovery.

Jack's employer is holding his job as a sound technician in the hope that he can eventually return. Given his rapid progress without any support or rehab, one can only wonder whether Jack might have been have been back at work by now if he had received the right support.

Julie
In her late twenties, Julie has Muscular Dystrophy and lives in a regional area. Already severely weakened, Julie is facing placement in an aged care facility in the near future.

The loss of her independence and home are not, however, the most important things she faces losing if she is placed in a nursing home. Julie has a 4 year old daughter, who also has Muscular Dystrophy. If Julie has to go into an aged care facility and cannot continue to be supported in community living arrangements, she faces losing her daughter too.

Melissa
The victim of an unprovoked assault when she was 16, Melissa has been left with a severe ABI as a result of this attack. Her parents were told she would be in a persistent vegetative state for the rest of her life and advised to place her in an aged care home.

They refused and fought to have their daughter accepted into Victoria's *Slow To Recover Program* (STR). This dedicated slow stream rehabilitation program for young people with ABI is unique in Australia and has remarkable success in returning young people with ABI to lives in the community.

After 2 years on the STR Program and now 18, Melissa is going home to live with her family later this year. But without the solid (financial) support of their local community, Melissa's

parents could not have afforded the extensive renovations to their home needed to enable Melissa to live there. Melissa is not eligible for personal injury compensation.

Jess
Jess was injured trying to stop a bolting horse when she was 22. She sustained major injuries to her spine and an ABI.

Now in their 80's, Jess' parents have cared for her since her injury at home. They have received no financial support or assistance to do this and are now extremely concerned about Jess' future once they are no longer able to support her.

Jess' dad has just had his second hip replacement and is not well himself. Her mother is also unwell.

Her parents have been trying to get some community based accommodation built in their local area for Jess and the many other young people with complex care needs who also need this type of support. They have not been successful and do not want Jess to be placed in an aged care facility. They and Jess face an uncertain future.

Rachel
Injured in a car accident when she was 16, Rachel spent nearly a year in hospital. Severely disabled, she went straight to an aged care nursing home because no community based accommodation existed in the regional town in which her family lived.

Now 34, Rachel has no friends and sees her brother sporadically. In the opinion of the Director of Nursing of the Nursing Home, Vicky's health and quality of life would be dramatically improved with access to rehabilitation. She receives no disability support services in the nursing home.

Despite receiving a compensation payout under an accident compensation scheme, Vicky was initially placed in an aged care facility because no other option existed at the time. Living in an aged care facility means that Vicky is no longer on the disability sector's 'radar' and has missed out on placement in community based living options that have been developed in her town since her accident.

A determined and optimistic young woman, Vicky continues to advocate for community based accommodation and support choices for herself and other young people with high care needs. She wants to be part of her community again.

Jason
Jason is 45 and has MS. The youngest person there, Jason lives in an aged care facility in a country area. The Nursing Home's resident population is predominantly made up of frail elderly people with dementia and Alzheimer's Disease.

Jason has to have the doorway to his room barricaded to prevent a resident wandering in and assaulting him.

Jason receives no rehab or other disability support and his condition is deteriorating as a result. As he does not have a wheelchair, he cannot get out of bed unless he sits in a water chair. He suffers from depression.

Jason wants to 'go out' to the movies and spend time with his family. He hasn't been out of the nursing home since he was placed there because he cannot obtain the disability funds he needs to access his community.

young people in nursing homes

creating a pathway from aged care to appropriate care

NATIONAL SUMMIT ON YOUNG PEOPLE IN NURSING HOMES
Melbourne, 2 May, 2002

CALL FOR ACTION

1. ***Bi-partisan agreement and commitment between major political parties and tiers of Government by 2004 to:***
   - *Direct resources **to enable young people in nursing homes to** access their life choices*
   - *Develop alternative housing and support options for younger people wishing to move out of nursing homes*
   - *Reduce further admission of younger people into nursing homes through the provision of flexible care packages to ensure they are able to access choices about where they live*
   - *Develop and implement research designed to complement the commitment to action, which is underpinned by the needs and experiences of young people and their families/friends, to identify:*
     Models of care, Extent of need, Costs and Resources
     required to provide alternative accommodation and support for younger people with disabilities needing a high level of care.

2. ***Measures and Resource Allocation built into the Commonwealth State Disability Agreement***
   - *Inclusion of performance targets for the States regarding the creation of alternative services for young people in nursing.*
   - *Add this cohort to the measurement of unmet demand in the calculation of growth funds.*
   - *Establishment of a Commonwealth State Working Group to resolve the funding responsibilities and ensure sustainable service **delivery.***

3. *Commonwealth to take leadership in resolving the issue of responsibilities and resources*
   - *The Departments must define and clarify areas of discrete fiscal responsibility for younger people in nursing homes.*
   - *Recognition that the resources available to meet these needs have not been adequate.*
   - *Revision of current policy regarding admission of younger people to residential aged care.*

Structures required to ensure sustained action and outcomes

- *Commonwealth and State Governments to establish a **National Body for YPINH** comprising representatives from Commonwealth, State Governments and all Stakeholder groups, including those directly affected, to oversight the implementation of the agreed strategies*
- *Establishment of **National Young People in Nursing Homes Advocacy Alliance** to coordinate lobbying efforts, form partnerships with and across health and community service sectors and ensure action occurs on the agreed strategies.*

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