youngpeople innursinghomes NATIONAL ALLIANCE

SENATE FINANCE AND PUBLIC ADMINISTRATION COMMITTEE

Inquiry into the Provisions of the Medibank Private Sale Bill 2006

Submission on

- The health and insurance markets across the states and territories and the overall access and equity implications for healthcare

Submitted by the *Young People In Nursing Homes National Alliance*
27 October 2006

The Young People In Nursing Homes National Alliance

The *Young People In Nursing Homes National Alliance* is a national organisation that promotes the rights of young disabled Australians with high and complex support needs living in residential aged care facilities or at risk of placement there, to have choice about where they live and how they are supported.

With offices in every state and territory and a national office based in Victoria, the *Alliance's* membership base is drawn from all stakeholder groups 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.

Working collaboratively with YPINH, their families and other stakeholders to develop the supported accommodation alternatives needed to achieve its aims, the Alliance encourages a partnership approach to resolution of the issue by State and Commonwealth governments.

In addition to encouraging governments to develop partnered responses, the National Alliance is committed to the development of choice in accommodation and support options; and to supporting young people and their families in the exercise of that choice.

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.

To achieve these aims, the Alliance works to develop policy initiatives at state and federal levels that promote the dignity, well being and independence of YPINH and their active participation in their communities; and ensure that young people living in nursing homes and their families have

- a voice about where they want to live and how they want to be supported
- the capacity to participate in efforts to achieve this, and
- 'a place of the table', so they can be directly involved in the service development needed to have "lives worth living" in the community.

Representatives of both jurisdictions and key Commonwealth and State bureaucrats work closely with the Alliance towards resolution of the YPINH issue.

The National Alliance is pleased the Senate has undertaken this inquiry into the sale of Medibank Private.

As well as reviewing the benefits or otherwise such a sale will deliver, the inquiry has the capacity to consider the access and equity implications for healthcare more generally as part of the national reform agenda in health. It is to this part of the enquiry's mandate that this submission is directed.

Australia's bifurcated system of long-term care and support has not coped well with the advances that modern medical technologies and improved health care have delivered. Those who have suffered acquired disabilities as the result of catastrophic injuries or the onset of degenerative neurological diseases now represent the most rapid area of growth because of these very advances.

Yet the antiquated long term care and support systems we maintain are falling further and further behind in their efforts to patch together a response that can even minimally accord with the expectations that communities now have. As a result, we face continual crisis in all areas of the health, aged care and disability systems as growing numbers of Australians are unable to access the long term care and support they need.

The Alliance recommends the following actions be undertaken to address this crisis.

1. **Development of a national strategy for long term care and support based on need not age.**

   Like most of the developed world, Australia faces increasing demands for long term care and support across the board. To date, the chronic under funding of disability services by all jurisdictions has meant responses to the growth in demand for long-term care and support have been reactive, lacked vision and been costly in terms of lives and available resources.

   Australia's existing long term care and support system also defines responsibility for long term care according to age, something that is outdated, ineffective and increasingly irrelevant in light of Australia's increasing longevity.

   Yet it continues to inform a fractured system of long term care and support that has neither the flexibility nor the capacity to deliver long term support across the board, regardless of age; and reduces support for individuals merely because they turn 65, despite the increase in disability that accompanies age.

   The inability to receive adequate long term care and support inevitably leads to deterioration in health and well being. It also means a growing (and costly) dependence on the various arms of the health system to make up the shortfall.

   Australians expect an efficient and effective system of long term care and support to be in place when they need it. They expect to access the supports and services they need, regardless of age.

The divided system we have cannot satisfy these expectations or the long term support needs of those needing its help.

2. **Sustainability of such a system delivered through a suite of funding options including**

   a. *No-fault insurance for catastrophic injury*

   While only Victoria, South Australia and Tasmania currently have no-fault insurance schemes in place for catastrophic injuries sustained in motor vehicle accidents, other states have shown an interest in moving their existing fault-based systems to no-fault schemes. As one example, New South Wales recently expanded its fault-based motor vehicle accident scheme to a no-fault basis for catastrophic injuries. Western Australia has shown a similar interest in expanding its fault-based motor accident scheme.

   Because it has adequate funding to deliver the rehabilitation, equipment and other support services that individuals with catastrophic injuries need, Victoria's *Transport Accident Commission* supports all but two of its clients in community-based, supported accommodation. The two clients that have chosen to live in aged care settings have done so because these are the only accommodation options that allow them to remain near their families and within their communities in remote areas. The Victorian government is presently investigating the expansion of that state's no-fault transport accident scheme to a no-fault scheme for catastrophic injury more generally.

   While such schemes cannot provide all the resourcing required for long term care and support, their successful resourcing of particular segments of need, such as catastrophic injury, mean that their contributions ease the burden of sustainability overall.

   b. *A social insurance levy*
   Similar in scope and intent to the Medicare levy that provides health care for all Australians, such a levy would be contructed to deliver long term care and support from point of diagnosis for the life span.

   Despite contributing to a range of insurance products including Medicare, private health insurance, workers compensation insurances and various transport accident schemes through car registration levies, Australians are still not comprehensively covered for long term care and support exigencies that arise because of unprovoked assaults, sporting accidents, or accidents of health and age (strokes, aneurysms, heart attacks). Yet because disability increases with age, it is likely that we all, at some point in life, will need support of some type and for varying periods of time.

   From discussions with a range of stakeholders, the Alliance believes there is strong community support for a social insurance levy for long term care, similar to the Medicare levy that provides access to health care for all Australians, as and when needed. Policy work around the

development of an effective and sustainable national long term care and support strategy must is imperative if the situation is to be improved.

3. **Expansion of jurisdictional partnership and collaboration.**
   To properly support an effective long term care and support strategy, funding and resourcing must be a collaborative partnership between Federal and State governments.

   The existing division of responsibilities has been ineffective in its efforts to deliver the long term care and support services Australians need. Reform of this reactive and under resourced system as part of the broader health reform agenda, is imperative.

   All jurisdictions need to embrace a collaborative approach to service development and provision that encourages a more effective distribution and sharing of resources, especially around access to rehabilitative therapies as recovery from catastrophic injury; and to maintain health and well being for those with degenerative neurological diseases.

4. **Conclusion**

While the Government is making plans for the health insurance industry, it should be also considering the impact on other forms of insurance/health /disability funding.

As one example, over one third (1/3) of young Australians living in residential aged care facilities (YPINH) have Multiple Sclerosis (MS). 70% of people with MS hold private health insurance - and yet their chronic illness management – especially long term care needs – cannot be well met through the Private Health Insurance system.[1]

The most effective way to address this situation is to have a broad premium base so that excellence in premium pricing/claims management can be delivered. This is something that has been successfully demonstrated for some considerable time by the Victorian Transport Commission's (TAC) premium pricing/claims management system. The TAC has over 3 million policy holders and collects enough premiums to cover the range of claims – including the catastrophic injury group – and still delivers a substantial dividend to the Victorian Government each year. In this sense, and as the TAC's example shows, a monopoly can work better than competition.

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[1] Access Economics *Acting Positively: Strategic implications of the economic costs of Multiple Sclerosis in Australia. Report by Access Economics for Multiple Sclerosis Australia*, Winter 2005: 87.

Breaking up Medibank Private will further splinter their extant premium base, making it harder for each of the companies now offering private health insurance to remain viable and set premiums based on the risk facing the entire community, not just the micro pricing and profit targets each company will want to sustain.

5. Case Studies

Grayden Moore

Grayden sustained an acquired brain injury as the result of a skateboarding accident. His journey since this accident has taken him to the brink of death several times and is indicative of a systemic failure to deliver the rehabilitative and health responses he needed to recover from this catastrophic injury.

Grayden's story is instructive because, despite having access to a range of insurances, Grayden was still unable to access the rehabilitative and other health supports he needed to recover. His mother says that Grayden's private health insurance was completely useless as far as getting the life saving health supports and services he needed. It has only been by dint of her untiring efforts on Grayden's behalf and her decision to fight for her son's right to access these services, that Grayden has been able to make the recovery he has.

Given that he has made the most remrkable of recoveries, against all odds and despite not having access to dedicated rehabilitation programs, one can only wonder what Grayden's recovery *might* have been, had he had the supports he needed, when he needed them.

Grayden's story declares the lack of access and equity in our existing health care system. It also indicates the desperate need for reform of current health care arrangements and the human and financial costs that will result if this is not done.

From *The Sydney Morning Herald*, September 15, 2006.

The Royal serves, and Grayden is back in match

Potential … Grayden Moore with his mother, Laurelie, at the Royal Rehabilitation Centre in Ryde, where he eventually received therapy after his accident.
Photo: *Ben Rushton*

Julie Robotham Medical Editor
September 15, 2006

A FALL from a skateboard ended the larger aspirations of Grayden Moore, a former junior tennis champion, who had travelled the world on the coaching and tournament circuit.

The head injury he sustained in 2004 caused irreparable damage to his brain and meant his family had to set their sights on more basic achievements.

Regaining some mobility, communication and relative physical comfort were as many positives as they could hope for. Mr Moore's mother, Laurelie, assumed the health system would be similarly committed to making the best of a bad job for her son. She was astounded when, after an initial six months of hospital treatment, he was transferred to an aged care nursing home, where he languished and deteriorated. "He went down to 49 kilograms. He was literally dying of failure to thrive," Mrs Moore said.

Transferred to the Royal Rehabilitation Centre at Ryde, Mr Moore began to make progress, and the not-for-profit Royal bent its rules to allow him to stay long-term in its Weemala assessment unit.

"They gave him the therapy he so desperately needed," said Mrs Moore of her son, now 25. "Now he's walking with a frame, he plays wheelchair tennis, he's touch-typing, emailing friends. His memory's coming back … He has to be given the chance of getting to his full potential. It doesn't happen by magic though. It happens with intensive therapy."

Mr Moore is one of a growing number of young people consigned to nursing homes designed around the reality that their frail elderly patients will not recover.

Pioneering surgery and new intensive care techniques have increased the chance of surviving shocking injuries, but this in turn has increased the number of younger people with permanent disabilities for whom there is no alternative accommodation.

In June last year 6449 people aged under 65 were in aged care homes across Australia, including 222 aged under 40, of whom at least 85 were in NSW.

The rehabilitation sector is urging state and federal governments to clarify how they will fund services for highly dependent younger people, after the premier's conference agreed this year to measures - calculated at about $80 million for NSW - to tackle the long-term rehabilitation needs of younger people.

Peter Williamson, CEO of the Royal, which is developing an $80 million accommodation facility for younger people, said those who received insurance payouts from vehicle accidents were generally well catered for. It was people like Mr Moore who were not entitled to compensation who "fall through the cracks, fall back into the public system", he said.

From *The Australian,* September 16, 2006
The forgotten ones

Thousands of young disabled patients must spend their lives in aged care homes. Kellie Bisset reports on attempts to get them out.

AUSTRALIA'S health and disability systems failed 26-year-old Grayden Moore. Two years ago a skateboarding accident left the promising young tennis player with a serious brain injury. And although hospitals in both Queensland and NSW were able to offer him lifesaving surgery, no one seemed to know quite what to do with him next.

As a result he ended up in a nursing home, unable to speak and barely able to move, and facing a bleak future surrounded by sick and dying patients three times his age. At one stage doctors even suggested he should be left to die peacefully – but his family refused to give up.

Nearly 18 months later, Grayden Moore can talk, walk with a frame, and chat over the internet. While not back to his former sporting standard, he's already shown an aptitude for wheelchair tennis – and even completed in last month's annual City to Surf fun run in Sydney, albeit in a wheelchair. He plans to do the run again next year – but without wheels.

His progress has delighted his mother Laurelei, a former nurse, and his father Derek, a GP, who describes his son's condition as "a slowly evolving miracle". But the only reason Grayden has come this far is because his parents fought the fight of their lives to get him out of the nursing home and into Weemala, an extended care service for disabled patients run by the non-profit Royal Rehabilitation Centre in Sydney.

After two failed attempts, and being told repeatedly that aged care was their only option, the Moores scored a victory over the system by refusing to continue paying for his nursing home bed, forcing his place to lapse.

"It has been an absolute nightmare that nearly tore us apart," Laurelei says. "You think 'they must be able to do something, we have paid our taxes, we have private health cover, he will be looked after' – and he absolutely was not. My husband's a doctor, my brother's a doctor, two of my children are doctors . . . and nothing helped."

Originally considered ineligible for rehabilitation, Grayden languished in a nursing home for several weeks after his surgery, sedated with high doses of anti-epileptic medication. This sent his body into a toxic coma and he was rushed back to hospital.

After narrowly surviving that trauma, he was sent back to the nursing home. Within two months his weight plummeted to 49kg. The home agreed to send him to the Royal Rehabilitation Centre for assessment.

"He was dying from malnutrition," Laurelei says. "From then on he really started improving very quickly . . . but after a few months it was suggested he go back to the home. We said 'No, he's not'. He nearly died twice because of that – it is a totally unsuitable place. The third time would have been the end of him."

According to Royal Rehabilitation Centre CEO Peter Williamson, Grayden's amazing recovery could be repeated many times if there was enough money in the system to assist people with an acquired brain injury on the long road to rehabilitation.

Instead, a lack of funds means more than 6000 people under 65 – including some as young as nine – languish in nursing homes for the rest of their lives, with little or no specialised care and no chance of re-integrating into the community.

Some of them have an acquired brain injury, some have neurological conditions such as multiple sclerosis and others have physical disabilities including spinal injury.

Many of those injured in catastrophic accidents fall outside the compensation system, which only covers motor vehicle accident victims, so they can't afford their own care.

For those patients with acquired brain injury, recovery can take two or more years. But, depending on which state they live in, inter-departmental buck-passing means they might be funded for a few months of rehabilitation via the health department and receive no long-term support from poorly funded disability services. So they end up in federally funded nursing homes.

Worryingly, the numbers of young people in this predicament are growing. The National Alliance of Young People in Nursing Homes estimates there will be more than 10,000 young people living in aged facilities by 2010.

"It is a hopeless system," Williamson says. "Our organisation has been advocating for at least six or seven years for a whole-of-government approach to this."

At last though, things seem to be moving. In February the Council of Australian Governments (COAG) committed $244 million over five years to cut the numbers of young people living in residential aged care. Following last year's Senate Inquiry into Aged Care, which urged action in this area, COAG has made assisting those under 50 a priority.

The funds will help set up alternative long- term care options, and help prevent young people entering nursing homes in the first place. Many have welcomed this as a great start, but experts warn it's crucial we don't mess up a golden opportunity by throwing dollars at inappropriate solutions.

"It could go either way," Williamson says.

"It is about being very smart and innovative to allocate these funds that will provide long-term solutions, not short-term quick fixes."

For Bronwyn Morkham, this money has been a long time coming. "This issue has been around for 40 years and nothing has been done." The national director of the National Alliance of Young People in Nursing Homes, she agrees the funds are a good start, but the unmet need is "chronic and astronomical".

"It is one of life's ironies that we spend so much money saving lives then we throw them on the scrap heap," Morkham says. "We have been remarkably fortunate to have access to the latest medical technologies . . . but we have been too successful for our own good. The growth in demand for long term care has been so astounding people have not seen it coming, and the system has been caught out."

Apart from appropriate medical care and rehabilitation, argues Trevor Parmenter (see column this page), it's quality of life, and a reason to wake up each day, that many young nursing home residents aren't getting.

An article published in Australian Health Review a few years ago (2002;25(3)) says the medical literature shows that proper social support aids rehabilitation.

"It is relationships and friendships and interaction with other people that are the basis for a good quality of life for them," Parmenter says. "We judge our society by the way it reaches out to these people. Until this (COAG) initiative, we really put them away and threw away the key."

Parmenter is director of the Centre for Developmental Disability Studies, based at the Royal Rehabilitation Centre.

He says the whole concept of effective rehabilitation is moving from bed-based to home-based support, and he's hoping the new funds might help patients move back into the community.

Adeline Hodgkinson, director of Sydney's Liverpool Hospital brain injury rehabilitation unit, says there are examples of different community care models that already work well – so there's no need to reinvent the wheel.

She says care models can include properly supporting families to provide care (though this happens rarely); providing 24-hour paid carers; offering daily, but not full-time care; group homes with a shared carer, or collections of individual units that pool care resources. Even blocking off sections of nursing homes themselves for young people has been flagged as an option.

The alternative is being transplanted from your own peer group to another, almost alien, generation. "Some young people might share a room with multiple people who come and go and die next to them and that might occur for 10 or 20 years, depending on how long you are there," Hodgkinson says.

The recent NSW state government announcement of a new 10-year plan for disability services, including $1 billion over the first five years, has raised hopes that along with the COAG plan, momentum might finally be building in NSW.

However, many point to Victoria as a role model for other jurisdictions. It runs the Acquired Brain Injury: Slow to Recover program, covering long-term funding for brain injured patients without accident compensation. But Morkham says there are thousands on the waiting list and staff members are fielding inquiries from desperate families in other states.

The Alliance says that every year, $372 million is wasted by keeping the frail aged in hospitals because they can't access a nursing home bed. If younger people were offered more suitable accommodation, it argues, beds would be freed up for the people who should really be there.

This "bed block" is evident elsewhere in the system. Young people also sit in hospitals waiting for rehab places taken up by patients with nowhere to move – and this delay affects their ability to recover.

Parmenter says there are also thousands of parents looking after disabled children who have never received a government service. As they age and become unable to cope, the pressure on the system to take in extra patients will build.

It seems COAG's intervention has come at a timely point, but progress is still slow. Only three states have so far signed bilateral agreements with the commonwealth to put the new funding system in place, and few, if any, decisions have been made on deciding what kind of services it should pay for.

Grayden Moore though, is an example of what can be done.

"This is the first place we have been in two years where the environment has been positive," his mother says. "The system failed us and it is failing all our young people. Grayden can't believe he was relegated to a nursing home – he was horrified by that and says thanks so much for fighting for me, and thanks for not giving up."

Angela Barker

When she was 16 years old, Angela was the victim of a vicious, unprovoked assault that left her barely alive and in a coma for several months. As a result of this attack, Angela was left with a massive Acquired Brain Injury.

Like many other young people in this position, her parents were told that Angela should be placed in an aged care nursing home and forgotten. Fortunately, her parents refused this prognosis and, like Grayden’s mother, fought to get their daughter the rehabilitation she needed to recover.

Because she was able to access Victoria’s Slow To Recover slow stream rehabilitation program and against all the odds, Angela has made a remarkable recovery. Unlike Grayden, Angela had no private health insurance. Like Grayden, her accident was non compensable and like him, had she been injured at work or in a Victorian registered car, she would have received rehabilitative and long term support benefits for the rest of her life.

Like Grayden, Angela exemplifies the lack of equity and access in our existing health care system. Her story again illustrates the point that despite paying for many different insurances, we are still not covered for some of life’s more unpredictable exigencies as the following table illustrates.

Disability Compensation Victoria

Services	Pain & Suffering compensation
Car Accident • all medicals, rehabilitation, disability support, wages	$400,310
WorkCover • all medicals, rehabilitation, disability support, wages	$406,000
Crime (Offender Broke) • medicals (6 years) and • wages (1-2 years)	$ 7,500
Disease, misadventure •public system, social security •aged care, 0.5% of disability housing	$ 0

As Grayden’s story has done, Angela’s story declares the need for a sustainable long term care and support system that uses no fault insurance for catastrophic injury in concert with a social insurance levy, to deliver viability.

6. References

Access Economics *Acting Positively: Strategic implications of the economic costs of Multiple Sclerosis in Australia. Report by Access Economics for Multiple Sclerosis Australia*, Winter 2005. (Copy attached)

Pricewaterhouse Coopers *Levels and Cost of Catastrophic Injuries from Motor Vehicle Accidents in Australia*, CT CTP Claims Management Symposium,16 June 2005. (Copy attached).