Submission No. 764
(Inq into better support for carers)

Aoc 15/7/08

House of Representatives Standing Committee on Family, Community, Housing and Youth

Inquiry into better support for carers

Submission on

- the role and contribution of carers in society and how this should be recognised;
- the barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment;
- the practical measures required to better support carers, including key priorities for action; and
- strategies to assist carers to access the same range of opportunities and choices as the wider community, including strategies to increase the capacity for carers to make choices within their caring roles, transition into and out of caring, and effectively plan for the future.

Submitted by the *Young People In Nursing Homes National Alliance*
5 July 2008

Summary of recommendations

1. Promote a case coordination approach to care and support that ensures families and carers are *partners* in the care of their loved ones, not simply the sole providers of that care.
2. Harmonise interfaces between health (acute and allied), disability, community services, housing and aged care systems through improved information and communication to ensure Australians with disability (and their carers), don't 'fall through the system's cracks'.
3. Instigate a national lifetime care and support strategy
4. Develop a better skilled disability support workforce that promotes retention of appropriately skilled workers through improved pay rates, recognition of particular skill sets, and the development of a career path for support workers.
5. Provide 'clinical overlays' or nursing backup as part of the essential disability supports and services required by those with acquired disability and high and complex health and support needs.
6. Develop a national Aids & Equipment scheme that responds to requests for assistance in a timely and effective manner across jurisdictions. Underpin this scheme with the growth of an Australian Aids & Equipment industry that can develop equipment suited to Australian needs and conditions; utilise our well recognized capacity for innovation and ingenuity; and retain the capacity to export.
7. Deliver tax deductibility to carers for purchases by carers of aids and equipment, services, and other essentials required for the care and support their loved ones
8. Ensure family carers of young Australians living in nursing homes are eligible for the carers pension and other benefits.

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.

1. Introduction

The National Alliance is pleased the House of Representatives Standing Committee on Family, Community, Housing and Youth has undertaken this inquiry into better support for carers.

In Australia today, many individuals with disability receive the support they need to live their lives through informal, unpaid care delivered by carers who are largely their families and friends.

This situation has arisen largely because chronic under funding has been the *sine qua non* of disability services in Australia for far too long. The result has been almost exponential growth in unmet need for services and the development of an army of informal carers who have stepped in to deliver the care their loved ones need in the absence of adequate or appropriate responses from the service system.

The Alliance firmly believes that the development of an adequately funded service system responsive to the changing needs and life circumstances of Australians with disability would obviate the need for carers to be the sole providers of care to their loved ones, making it possible for them to be partners in that care instead. Achieving this would not only benefit carers by enabling them to regain lives put on hold while they cared, with all the personal and economic benefits this will deliver. It would also benefit individuals requiring lifetime care and support by enabling them to have the independence and dignity that comes with directing their own support workers in pursuit of a 'life worth living'.

Delivering such an outcome is dependent, however, on the development of a well trained workforce, skilled in the depth and complexity of support need that those with acquired disability require. To that end, the Alliance supports the development of a career structure for support workers that focuses on improved training and retention of highly skilled workers through

- Improved pay rates for support workers
- Financial incentive for the development of advanced skill sets
- Paid study leave to workers who wish to improve their skills
- Opportunities for secondment or reciprocal exchange to enable direct experience of innovative support services in Australia and overseas
- Advancement opportunities to management level and beyond

Without initiatives such as these, informal unpaid – and unrecognized – care will remain the cornerstone of the disability support system. We will all be the poorer if that happens.

2. Young People In Nursing Homes (YPINH)

Like other Australians with disability, Young People In Nursing Homes (YPINH) and others with high and complex health and support needs find themselves struggling to access the in home or community based supports they need.

Largely comprised of individuals with acquired disabilities, many YPINH have sustained catastrophic injuries in situations where compensation is not available. There is also a significant group that has developed degenerative neurological diseases, requiring an episodic approach to their care and support. 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.

This almost infinite variety of cause declares three stark facts. First, that any one of us could acquire disability through accident or illness that requires high and complex levels of support. 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 for both the individual concerned and for their families. Third, that the existing support system is so incapable of delivering the supports this group with acquired disabilities requires, that informal care is often the only alternative to institutional care.

3. Impact of inadequate funding

Young people with high and/or complex support needs arrive at the door of the disability system without warning. Their different and more costly support requirements and the acute yet often unpredictable nature of the demands they make of the allied health, acute care and disability systems means that current funding arrangements deliver an almost constant funding shortfall for this group, if they are able to access services at all.

The net result is twofold. First, ever increasing numbers of young Australians with acquired disability and high and complex support needs are ending up in aged care nursing homes because they supports and services they need to live in the community do not exist. When this happens, it is often because the informal care they depend on to remain in the community has broken down; or their health and support needs have exceeded their carers' capacity to provide for.

Second, in an effort to remain living in the community, unknown numbers of young Australians with high and complex health and support needs struggle with inadequate services and supports, dependent on the informal care delivered by families and friends. In both instances, the impact on informal carers and the loved ones they care for is devastating.

Their complex support requirements also means that young people with acquired disabilities may need to access the health, acute care, disability and aged care systems (for nursing levels of care) from time to time. Where access to these supports and services is unavailable, carers experience an almost irreversible breakdown in their health and physical well-being over time. There are numerous instances of family members who have provided informal care to their loved ones over many years who end up requiring multiple joint replacements because joints have worn out lifting, turning and transferring a family member with high and complex support needs.

So too, caring takes a heavy toll on the financial capacity of carers. For those with acquired disability, the complexity of care arrangements means that paid work must usually be relinquished and savings used up in an effort to make ends meet. Disability is an expensive occupation and too often, financial ruin and a life of poverty is the only reward for carers who actively support their loved ones with acquired disability.

For those who do end up in nursing homes because their informal care arrangements have broken down, placement in residential aged care is a disaster. By the time this happens, carers have acquired their own health issues as a result of the care they have provided and are often left in need of care themselves. They experience enormous guilt, depression and anguish when a loved one is placed in residential aged care, feeling they have failed their family member and should have been able to do more.

The net result is that instead of one group of individuals needing high levels of care and support, we end up with two. The cost to the economy in terms of lost wages and spending, retraction of the tax base, increased demand for already overburdened health, disability and aged care services as well as the huge rise in costs that attends larger and larger numbers of people needing lifetime care and support, is massive.

4. Recommendations

The YPINH National Alliance believes the following recommendations must be addressed if a sustainable and equitable lifetime care and support service system is to be developed for young Australians with disability. Developing such a system will finally enable carers to become partners in the care and support of their loved ones; and deliver the independence and dignity young people with disability want… and deserve.

4.1 Promote a case coordination approach that ensures families and carers are partners in the care of their loved ones, not simply the sole providers of that care.

There is a real need for a case coordination approach to the delivery of care and support for individuals with acquired disability. The complexity of their health and support needs means that case management is often limited in its capacity to involve disparate services and 'joint the [support] dots' for those with complex support needs.

A case coordinator who has the capacity to 'walk the journey' with the individual and their carers, however, and is charged with maintaining information and contact with the various arms of the service system involved in delivering care, can offer timely and effective responses to changes in the individual's – or the carer's – needs and circumstances.

Rather than simply organising the supply of services, a case coordinator will take a preventative, proactive approach that

- involves carers as partners in the support of their loved one

- recognizes the needs, aspirations and wishes of the individual needing support
- and tries to anticipate changes in need or expectation that may be 'coming down the pipeline'.

4.2 *Harmonise interfaces between health (acute and allied), disability, community services, housing and aged care systems through improved information and communication to ensure Australians with disability (and their carers), don't 'fall through the system's cracks'.*

The service system is a challenge for even the most experienced to navigate. Presently disparate arms of the service system including health (acute care and allied health services), housing, disability services (personal support and respite services, aids and equipment et al), community services and aged care, have little (official) need for contact with each other and rarely collaborate in a systematic or proactive way. Yet young Australians with high and complex support needs often require involvement of these different parts of the service system in various ways and at often unpredictable times.

The service system's fragmentation and lack of collaboration and coordination means that where access to these disparate services is required, the burden of finding, coordinating and maintaining this support usually falls to carers.

Case managers – where available – are poorly resourced and are often expected to deal only with their own 'patch'. Opportunities to become better informed or to establish working relationships with other professionals outside their area of expertise and/or responsibility are limited and there is the enduring battle of under resoucing to contend with daily. No wonder reactionary, crisis driven approaches have become the norm!

Harmonising the interfaces between the different arms of the service system would deliver a better integrated, proactive approach to the delivery of care and support, not only for individuals with high and complex support needs but for all Australians with disability. Doing so would also remove a huge weight from the shoulders of carers and deliver a better quality of life to all concerned.

4.3 *Instigate a national lifetime care and support strategy.*

Like most of the developed world, Australia faces increasing demands for long term care and support across the board. This situation has arisen for two reasons.

The first is our access to sophisticated medical technologies that now save lives that once would have been lost, but leave the individual with significant acquired disabilities as a result. The second is our access to a world class health system that enables us all to live longer and with a better quality of life as we do. The net result has been an exponential growth in demand for long-term care and support, a situation that will continue to increase until we achieve the capacity to restore damaged bodies and minds to health and independence.

State disability systems that have developed in response to the less intense, more predictable needs of those with congenital disabilities, have never quite kept up with the growing demand for long term care and support that our health system has delivered. Young people who survive catastrophic injuries and unpredictable health events like asthma attacks or strokes, but are left with acquired disabilities, find that existing, state based systems are ill equipped to handle these different, more intense needs.

To date, the chronic under funding of disability services by all jurisdictions has meant responses to the growth in demand for lifetime 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 care according to age, something that is outdated, ineffective and increasingly irrelevant in light of Australian's increasing longevity.[1]

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

The inability to receive adequate lifetime 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. If, for example, the lack of a pressure mattress leads to pressure sores, the end cost will be many times greater than the original cost of the pressure mattress because of the consequent need for hospitalisation for extended periods and the use of allied health resources in recovery.

Australians expect an efficient and effective system of life time 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 life time support needs of those needing its help.

A properly integrated and effective lifetime care and support system must

- embrace a disability support system based on need not age and adopt a 'whole of life' approach to planning and management of disability resources.

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[1] This is something the previous Prime Minister, John Howard, himself acknowledged in his call for people to continue working into their 70's. In response to the 'greying of Australia', the Howard government urged Australians "...to work beyond the current average retirement age and introduced the pension bonus system in 1998 to encourage people to continue in paid work and defer receipt of the aged pension. The government also rejected recommendations of the Senate Inquiry in 2000 that the superannuation guarantee contribution by employers be raised from 9 to 15 per cent. Yet this is another indicator that many of the assumptions which people had about work and retirement are no longer valid and that the expectation of economic security in old age provided by either the employer or the government will not apply in the future..." Lansbury, R. and Baird, M. "Broadening the Horizons of HRM: Lessons for Australia from Experience of the United States", *Work & Organisational Studies Working Paper*, #WPC 00014, University of Sydney, September 2004. Web Reference: http://web.mit.edu/workplacecenter/docs/wpc0014.pdf

- be proactive about areas of jurisdictional gap and overlap and encourage sectors and jurisdictions to adopt a collaborative approach with regard to resources and funding.
- quarantine or segment critical service areas - such as young people with high/complex support needs - to ensure effort and funding can satisfy strategic goals and agreed outcomes.

If Australians are to receive the supports they need when they need them, an expanded and more efficient system of lifetime care and support built on a sustainable funding base, will be required.

To achieve this, the Alliance believes that a suite of funding options is needed to sustain such an expanded, effective and equitable system. These funding options should include capacity for national no fault insurance for catastrophic injuries; a social insurance levy for long term care and support similar in scope and intent to the Medicare levy; and compulsory taxation levies or duties.

a) National 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 lifetime 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) Lifetime care and support levy
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 lifetime 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 lifetime care and support strategy is essential if the current under resourcing of the service system is to be proactively addressed.

Without a dedicated funding stream to address the growth in demand for disability supports and services, people with disability and their carers will remain in a situation where needs cannot be adequately addressed and carers will continue to compromise their health and their livelihoods to care for their loved ones. That such a situation continues to exist in a country as wealthy as Australia, is a national disgrace.

4.4 Develop a better skilled disability support workforce through improved pay rates, recognition of particular skill sets, and the development of a career path for support workers that promotes retention of appropriately skilled workers.

The growth in demand that all areas of disability service and support have experienced has not been matched by the concomitant growth of a skilled and committed workforce. Part of the problem lies in poor rates of pay and the lack of a career structure that might otherwise encourage dedicated and skilled workers to remain over the long-term.

The result has been a transient population of disability support workers who take on the role when "nothing better" is in the offing and leave as soon as a job with better pay and prospects comes along. The manager of a country Victorian disability service has described how she lost eight of her most experienced workers in one day when a Target store opened in a nearby country town. The attraction was not only a reliable eight-hour shift each day and less strenuous work and less travel, but the much better rates of pay shop assistants received, compared to disability support workers.

Responsibility also lies with inadequate training provided by now ubiquitous TAFE courses in aged care and disability.[2] These courses no longer provide dedicated training in the different support needs that disabilities deriving from Multiple Sclerosis (MS), Pompe's Disease or Acquired Brain Injuries (ABI), for example, may require.

Anecdotal evidence from some service providers indicates that they would rather train a worker from scratch than take some of the workers they have employed as graduates

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[2] TAFE Institutes nationally offer Certificate IV in Disability Work, Certificate IV in Disability Work (Pathways to Community Service Work); Certificate III in Home and Community Care; Certificate III in Aged Care Work.

of Certificate 3 and 4 courses who come with poor understandings of their roles and inappropriate attitudes to client dignity and independence. Comment from TAFE trainers in these courses indicates that the funding they receive to deliver these courses has also been dramatically reduced. One TAFE institution in metropolitan Melbourne indicated that its funding for providing Certificate courses in disability was at an all-time low of something less than $5 per student, compared with nearly $16 per student the same institution received to offer training in injection moulding.

The economic and societal undervaluing of disability (and aged care) support workers must stop and a decent career structure introduced that recognises the vital nature of this work through improved rates of pay and promotion opportunities. These moves should be accompanied by improvements in training that deliver skilled workers committed to the dignity and independence of those they support.

4.5 Deliver 'clinical overlays' or nursing backup as part of the essential disability supports and services required by those with acquired disability and high and complex health and support needs.

At present, nursing levels of care can only be accessed in aged care nursing homes. The disability sector does not provide this level of care.

Yet young people with high and complex support needs require nursing levels of care from time to time to cope with exacerbations of chronic illnesses like Parkinson's Disease or Multiple Sclerosis; in the course of rehabilitation after catastrophic injury; or as part of their long term care and support requirements.

The fact that the group of young Australians with acquired disability and high and complex support needs is growing, means federal and state jurisdictions must recognize this fact and make provision to deliver nursing levels of care to this growth group, where and when required.

So too, the development of suitably trained and experienced support workers, skilled in supporting individuals with high and complex health and support needs, is an area of increasing need in the disability support landscape. As well as advanced training, clinical overlays or nursing backup needs to be in place to properly support and mentor workers who deliver support to individuals with this complexity of care need. Ensuring professional oversight of the care team is in place means that demands on carers are minimized and a more effective level of support is delivered to the individual with disability.

4.6 Develop a national Aids & Equipment scheme that responds to requests for assistance in a timely and effective manner across jurisdictions. Underpin the scheme with the growth of an Australian Aids & Equipment industry that can develop equipment suited to Australian needs and conditions, utilises our well recognized capacity for innovation and ingenuity and retains the capacity to export.

Having the right equipment is vital to maintenance of health and well being for people with disabilities. Yet access to much needed equipment is unacceptably limited because equipment subsidies are chronically under funded.

The stories of people having to make do with ill-fitting wheelchairs that cause enduring pain or unable to access the right pressure mattress because the subsidy provided by an Aids and Equipment program is too small, are legendary. And because a disability pension offers little hope of saving the shortfall, these prolonged delays ultimately contribute to deterioration in their health while individuals wait to rise to the top of the queue.

One young woman with very high support needs who requires splints on both legs to prevent shortening of her tendons and thus maintain her capacity to do standing transfers, has had to forego personal support in an effort to use the funds thus saved to purchase the splints. Maintaining this level of independence is vital if she is to continue living in her own home with support… a cheaper alternative for government than moving her to a more costly supported accommodation setting.

Another young man with an ABI only received an electric wheelchair when his local community saw his plight and raised the funds needed to purchase the wheelchair and some limited rehabilitation. Without his wheelchair, the young man would have remained permanently in his bed and been at serious risk of skin breakdown (pressure sores) and consequent (and costly) hospitalization.

In both these cases, delays in accessing much needed equipment would have led to diminution of health and independence and a consequent increase in the health and support costs borne by government. These cases illustrate the false economy that ensues when Australians with disabilities cannot access.the equipment they need.

The National Alliance believes an adequately funded national aids and equipment program would not only deliver the much needed equipment Australians with disabilities require to maintain health and independence; it would also save money by reducing health and support costs that devolve from a lessening of health and well being in both individuals with disability and their carers.

4.7 *Deliver tax deductibility for purchases by carers of aids and equipment, services, and other essentials required for the care and support of their loved ones.*

The under resourcing of the disability service system and the long wait times for a response, often results in a carer themselves buying the equipment or service their loved one requires. Unfortunately, the existing taxation system does not offer tax deductibility for such purchases where they are not for the specific use of the purchaser.

The financial contributions carers make through purchasing goods and services for their family members should be recognized by making such purchases tax deductible.

4.8 *Ensure family carers of young Australians living in nursing homes are eligible for the carers pension and associated benefits.*

Because aged care facilities are not designed to cater for the very different, 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.

Residential aged care is unsuited to the growing need for accommodation and support for young people with high and complex care needs because

- 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.

Family carers of young Australians living in aged care nursing homes often necessarily spend significant amounts of time and energy providing personal support and care to their loved ones and do so at often considerable personal and financial cost.

This commitment should be recognized by ensuring that family carers of young people living in nursing homes can access carer's entitlements as other carers of individuals of disability do.