Young People in Nursing Homes National Alliance

# SENATE COMMUNITY AFFAIRS REFERENCES COMMITTEE

## Inquiry into the funding and operation of the Commonwealth State/Territory Disability Agreement

**Submission on**

- the intent and effect of the three CSTDAs to date;
- the appropriateness or otherwise of current Commonwealth/State/Territory joint funding arrangements, including an analysis of levels of unmet needs and, in particular, the unmet need for accommodation services and support;
- the ageing/disability interface with respect to health, aged care and other services, including the problems of jurisdictional overlap and inefficiency; and
- alternative funding, jurisdiction and administrative arrangements, including relevant examples from overseas.

**Submitted by the *Young People In Nursing Homes National Alliance***
**4 August 2006**

## Summary of recommendations

To redress the inequities previous agreements have delivered and develop a sustainable long term care and support strategy, the Alliance makes the following recommendations:

1. **Funding and outcomes**

   Funding must be significantly increased to deal with unmet need and exponential growth in demand for services. The targeted strategy adopted by the COAG initiative for YPINH that develops and directs services to a particular group, represents the type of approach the Alliance believes the 4th CSTDA should embrace. Issue based and outcome focused, such a coordinated response would declare each industry segment's strategies and funding as well as measurable inputs and outcomes for each jurisdiction and its industry partners.

2. **Sustainable long term care and support strategy**

   The 4th CSTDA needs to incorporate a proactive strategy for sustainable long term care and support based on need not age, with funding delivered via a suite of funding options including no-fault insurance for catastrophic injury and a social insurance levy for long term care and support. An appropriate career structure with improved rates of pay and training is imperative if support workers are to be valued and retained.

3. **Rehabilitation and Allied Health Supports**

   Enacting a national rehabilitation strategy will deliver opportunities for rehabilitation and recovery that are currently denied to individuals with acquired and complex disabilities. A national equipment strategy that ensures the equipment needed to maintain health and quality of life is delivered with flexibility and efficiency, is an integral part of both an effective rehabilitation strategy and the maintenance of health and well being for young disabled Australians. The 4th CSTDA must also make provision for nursing levels of care to be available to young people with high and complex support needs, as and when required; and incorporate improved case management strategies to ensure monitoring of needs and timely service responses for young people with acquired disabilities.

**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 Senate has undertaken this inquiry into the efficacy of the CSTDA as a national funding instrument for disability services.

It is clear that the previous three agreements have not been able to deliver the planning or resources needed to cope with exponential growth in demand for disability supports and services; nor the increased expectations and desire for involvement consumers now have about the services they need.

COAG's recent announcement of a partnership between Commonwealth, State and Territory Governments to start redressing the Young People In Nursing Homes (YPINH) issue, has fundamentally changed the way both jurisdictions will do business with each other around their shared responsibilities for disability planning and service provision in the future. [1]

As one example, the 50/50 *per capita* funding split that all jurisdictions have agreed to in the COAG initiative, means that future funding arrangements around disability service planning and provision are unlikely to return to the 80/20 funding formulas the current CSTDA agreement contains.[2]

This landmark agreement around YPINH has also established a benchmark for collaborative, proactive engagement in areas of joint jurisdictional responsibility with regard to disability planning and service provision; and a targeted approach to the needs of a particular group with clearly defined - and agreed - outcomes. Such an approach offers a positive way forward for jurisdictional negotiations around future CSTDA agreements.

While it has been agreed by all jurisdictions that the COAG initiative represents the first step on the path to final resolution of the YPINH issue, the process it embodies and the funding arrangements it contains offers a newly invigorated and very positive approach to tackling the systemic issues that have given birth to the YPINH problem.

In light of this newly proactive approach, new CSTDA agreements must recognize the increased costs those with complex and high support needs carry and deliver funding adequate to the provision of appropriate levels of service and support for this group. If this is not done, we can expect 'more of the same' systemic inefficiency and impoverished service provision that the disability sector has born for too long and which has seen unmet need grow to previously unthinkable heights.

---

[1] See the COAG Communiqué, February 10 2006, available at http://www.coag.gov.au/meetings/100206/index.htm

[2] Under this arrangement, the Commonwealth provided 20% of the funding while the States and Territories contributed an average 80%. Some states contributed more than 80%. The ACT, for example contributed 84% of the total disability funding available under its last CSTDA Agreement with Commonwealth. See Schedule A1, page 28 of the current CSTDA agreement, available at http://www.facs.gov.au/internet/facsinternet.nsf/via/cstda/$file/cstda_June06.rtf

Post the COAG agreement on YPINH, the challenge for any future CSTDA agreements will be to

- deliver the substantial funding needed to address unmet need and increase systemic capacity to prevent young people entering residential aged care in the future
- address areas of jurisdictional overlap and inefficiency and
- develop truly collaborative working relationships between Commonwealth and Sate and Territory jurisdictions that enable positive reform of existing systems and responsibilities.

As a first world nation, Australia has the economic capacity and a moral and ethical obligation to ensure that its most needy and vulnerable citizens have the supports they need to enact their citizenship as fully as possible.

Without significant reform and jurisdictional collaboration, the CSTDA will not be able to deliver the services and supports Australia's growing population of disabled individuals requires, now or in the future.

## 2. YPINH and the CSTDA

Under the three agreements to date, all parties have been responsible for funding specialist services for people with disabilities. All three agreements have been marked by evident goodwill and a desire to provide the services and supports Australians with disabilities need.

However, the transfer of administrative responsibility and funding that the first CSDA agreement instigated between the Australian Government and State and Territory Governments, occurred without adequate capacity for flexibility and growth. The second CSDA agreement included a commitment to revisit unmet need funding during the life of that Agreement, while the third focused on five strategic policy priorities involving improved access to generic services for people with disabilities; strengthening across government linkages; improved support for individuals, families and carers; better strategies to manage specialist disability services demand in the long term; and improved accountability, performance reporting and quality.

Yet over the life of these three Agreements, unmet need has continued to rise and growing numbers of disabled Australians have been forced to eke out an existence without the supports they need to be active and contributing members of their communities.

The existence of the YPINH issue and the consequent relegation of young Australians with high and/or complex support needs to inappropriate accommodation in aged care facilities and an endemic lack of rehabilitation and other vital supports needed to regain - and sustain - lives of dignity and independence for this group, represents the failure of these first three Agreements to achieve their declared aims.

The poor capacity of the CSTDA sector that successive agreements have delivered, has created state based disability systems - already struggling to meet growing demand -

unable to address the needs of people resident in Commonwealth funded facilities. Because of this, and despite being part of the CSTDA target group, YPINH have thus been unable to access the disability funds and resources that are otherwise available under this agreement to other young Australians with disabilities.

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 primary reasons for young people with high and/or complex support needs ending up in aged care facilities.

Despite their eligibility for CSTDA services under the various Commonwealth and State Disability Services Acts, younger people with disabilities living in the aged care system continue to be unable to access services under this agreement and are not included in the group identified by the Australian Institute of Health and Welfare as the 'unmet need' cluster who wait for disability services through the CSTDA.[3] As such, YPINH are not considered by the Commonwealth Government in its management planning of the national disability services system.

The current arrangements have enabled a system in which 70 % of those who receive services through the CSTDA have an intellectual disability, while over 80% of young people in aged care facilities have an acquired disability. More than any other, this statistic alone indicates the CSTDA sector's incapacity 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. Yet this group remains significantly underrepresented in the disability accommodation sector that is dominated by intellectual disability and congenital conditions and resourced through existing CSTDA arrangements. As one example, specific housing services for this neurological group in Victoria comprise 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 - although administratively attractive - this cannot be done *because the services required simply do not exist*. Without significant service development and reform to existing systems through the aegis of future CSTDA agreements, this situation will sustain and grow.

The three Agreements to date have clearly not been able to deliver strategic planning around future funding arrangements for this group. Nor have they been able to address the need for significant increases in funding to cope with unmet need more generally that this group also represents. 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

---

[3] *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

first CSDA is instructive in this regard.[4] The problems identified in that report remain and have deepened since its publication in 1996.

The CSTDA 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 former Minister for Family and Community Services, Amanda Vanstone, to instate an 80:20 funding arrangement in the third agreement 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, or at risk of placement, in residential aged care settings.

## 3. Funding and Outcomes

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 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.

YPINH need to be quarantined within any future CSTDA arrangements to ensure that adequate levels of funding are available to this group, as and when needed. Their complex support requirements means that they may need to access the health, acute care, disability and aged care systems (for nursing levels of care) from time to time. Future CSTDA agreements must therefore incorporate funding 'portability' so that disability funds can follow young people with complex care needs into whatever part of the health system they need to access - including aged nursing care - and provide for their different support needs while they reside there.

As well as facilitating access to equipment, these additional disability funds must allow therapy, recreational and other rehabilitative services to be put into place as well as access to nursing levels of care, as and when needed. They will also enable the increased staffing levels required to cope with the different, more intensive needs of YPINH and facilitate improved training of disability support workers and aged care staff in their support needs.

In short, the CSTDA needs to be restructured to

- address the increase in demand for disability services now and in the future[5];

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

[5] In its 2002 report, 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

- incorporate segmentation so that appropriate funding levels relevant to the identified need and associated costs of particular groups, such as YPINH and those with chronic illnesses, can be delivered; and
- increase its capacity to deliver the cross jurisdictional cooperation that resolution of the YPINH issue needs now, and long term care and support initiatives will require in the future.

## *3.1 Recommendations: Funding and Outcomes*

### 3.1.1 Partnership and collaboration:

Disability policy, funding and resourcing must be a proactive partnership between Federal and State and Territory governments that encourages cross jurisdictional cooperation and sharing of resources across jurisdictions and sectors.

### 3.2.1 Unmet need and segmentation

Unmet need must be addressed through significant funding increases and a strategic approach that recognizes the growing cost of service provision. YPINH and others, including those with chronic illness, have different, more intense and/or complex needs that must be recognized and a concomitant level of funding provided for the delivery of services and supports within future agreements. Access to nursing levels of care must also become part of the suite of disability services and supports future CSTDA agreements incorporate for this and other groups.

### 3.3.1 Strategic policy directions and agreed outcomes

Clearly articulated strategies - including agreed outcomes - have been lacking in previous agreements. The Alliance supports the development of agreed outcomes relevant to the delivery of services and supports to segments of the disability population, including service delivery arrangements with providers.

### 3.4.1 Outcome based funding

One of the biggest problems previous agreements have faced has been the lack of clearly articulated, outcome based funding arrangements. The COAG YPINH bi-lateral agreements are based on agreed outcomes and a funding process dependent on the achievement of these agreed outcomes. The Alliance would like to see similar arrangements in place as part of any future CSTDA agreements.

---

received. 77,900 did not have a fall-back carer at all. 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.
See AIHW *Unmet Need for Disability Services: Effectiveness of Funding and Remaining Shortfalls*, 2002. Available at http://www.aihw.gov.au/publications/index.cfm/title/7741

### 3.5.1 Transparency and accountability

While previous agreements have done much to improve transparency and accountability, more remains to be done. Future agreements should make provisions for transparency and accountability evident to all stakeholders, including consumers; and applicable to all participants, including service providers.

### 3.6.1 Whole of life planning for consumers

At present, the poor capacity of the CSTDA sector means that support needs are identified only through crisis interventions and often addressed too late to prevent costly deterioration in consumers' health. The YPINH group is illustrative of the need to move away from the ad hoc and reactive approach to service provision and resourcing that has become the norm under previous, insufficiently funded agreements.

The minute an individual is identified to be in need of disability support and resourcing, a 'whole of life' planning process should be activated that includes regular review of active need and the service responses that have been made to that point. Doing so will enable proactive planning for future need that enables service responses to be identified and planning begun, well in advance of the time these supports will need to be activated.

An effective, on going system of case management is also needed to ensure that individuals are tracked and adequately supported from the moment need is identified. Case managers should have the capacity - and training - to bring all those involved in the support of the individual - including the young person concerned, family members and friends, medical and allied health representatives and service providers - to the table to collaborate in the development of appropriate support arrangements.

### 3.7.1 Respite funding and access

The poor capacity of the CSTDA sector means that carers and families have become an integral part of the support regimes consumers require, often at great physical and personal cost. An Access Economics report commissioned by Carers Australia revealed that approximately 2.6 million or 1 in 8 Australians provide 1.2 billion hours of informal care at a cost of some $31 billion annually.[6] When measured as a reduction in paid employment due to caring, the cost was equal to $4.9 billion or 0.5% of GDP. Many of these family based support arrangements involve ageing carers who are increasingly unable to deliver the support their loved ones require.

Until the CSTDA sector can adequately deliver the services and supports all disabled Australians require, informal carers will continue to provide the shortfall. Funding and access to respite needs must be drastically increased if informal carers are to continue providing this vital support.

---

[6] *The Economic Value of Informal Care*, Access Economics for Carers Australia, 2005. Available at http://www.carersaustralia.com.au/images/stories/Access%20Economics%20study%20full.pdf

## 4. National Long Term Care and Support strategy

### *4.1 Rising demand*

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 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.[7]

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.

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

[7] This is something the Prime Minister himself has acknowledged in his call for people to continue working into their 70's. In response to the 'greying of Australia', the Howard government has 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

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 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.

Future CSTDA agreements 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.
- 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.

### *4.2 Resourcing and sustainability*

Previous agreements have concentrated almost exclusively on models of service delivery and innovative approaches to service provision. While this work has delivered new understandings in these areas, it hasn't adequately addressed issues around funding and sustainability. If Australians are to receive the supports they need when they need them, an expanded and more efficient system of long term 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.

#### 4.2.1 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.

### 4.2.2 Social insurance levy for long term care and support

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 should be included in the 4th CSTDA.

## *4.3 Workforce and training*

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 a reliable eight-hour shift each day, 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.[8] 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.

[8] 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.

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 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.

### *4.4 Recommendations: long term care and support*

**4.4.1 Inequities in the existing system must be addressed through the development of a long term care and support system based on need not age.**

**4.4.2 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.

**4.4.3 Instate 'whole of life' planning for disability services and resources**

**4.4.4 Sustainable funding for long term care and support** must be developed through a suite of funding options including no-fault insurance for catastrophic injury and a social insurance levy.

**4.4.5 Individualised funding models** that are flexible in approach, have portability across sectors and jurisdictions and deliver packages that match designated service delivery models must be incorporated.

**4.4.6 Growing a better skilled and committed workforce** will depend on improved training for support workers and the development of an attractive career structure that incorporates professional rates of pay. Attitudes of workers to the people they support must be addressed in training that promotes the dignity and independence of individuals supported.

## 5 Rehabilitation and Allied Health Supports

### *5.2 National Rehabilitation Strategy*

Rehabilitation is both an integral part of recovery from catastrophic injury and a vital part of maintaining health and well being for many individuals with disabilities. This is especially true for young people with high and complex support needs.

At present, Australia lacks a comprehensive rehabilitation strategy as part of the suite of services it offers individuals with disabilities. Where rehabilitation programs do exist, their resourcing is so limited that the minimal amount of rehab they offer does little more than 'scratch the surface' of the long term needs individuals have.

Victoria's *Slow To Recover (STR)* slow stream rehabilitation program for young Victorians with Acquired Brain Injuries (ABI) is a case in point.[9] Developed initially as a measure to prevent young people with ABI entering residential aged care settings, the *STR Program* has been successful in delivering improved levels of recovery and competence to those fortunate enough to access the 2 year program.

Because this is the only program of its type in Australia, applicants from other states are increasingly applying for entry. Yet demand for access to the program far exceeds places available and a wait of some years is now in place for access. This is particularly disturbing in light of accepted thinking that the prospects for recovery from brain injury diminish the longer rehabilitative treatment is delayed.

Not only are too many Victorians queuing to access *STR*; many who have successfully completed the program but still need a modicum of rehabilitation to sustain the improvements in function they have gained, gradually lose access even to 'maintenance' supports because of the chronic under funding of the scheme.

Too many young Australians are being denied the opportunities they should have had to recover or regain physical, emotional and cognitive independence after catastrophic injury or debilitating health event. The cost to government in terms of increased *per capita* support costs for individuals denied these opportunities for recovery, is massive. The cost of these lost opportunities to the individuals who need them, is incalculable.

The Alliance believes a national rehabilitation strategy is imperative if long term support costs are to be reduced and individuals given the opportunities needed for recovery and maintenance of their health and well being over the long term.

### *5.3 National Equipment Strategy*

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

[9] Information about *STR* is available at
http://www.southernhealth.org.au/acquired_brain/acquired_brain_injury.htm
A review of the program's operation is available at
http://www.health.vic.gov.au/agedcare/downloads/abi_str_report.pdf#search=%22slow%20to%20recover%20program%22

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 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.

### *5.4 Access to nursing levels of care for individuals with high and complex 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.

Future CSTDA agreements must recognize this fact and make provision to deliver nursing levels of care to young Australians with high and complex support needs, where and when required.

### *5.4 Recommendations: rehabilitation and allied health supports*

The 4th CSTDA must contain

1. **A national rehabilitation strategy** that offers opportunities for rehabilitation and recovery to individuals with acquired disabilities and delivers

   a. better health and support outcomes for young disabled Australians with high and complex support needs and
   b. improved cost management for this group over the long term
2. **A national equipment strategy** which ensures that equipment needed to maintain health and quality of life are delivered with flexibility and efficiency.
3. **Access to nursing levels of care** for individuals with high and complex support needs

## References

Access Economics *The Economic Value of Informal Care*, Access Economics for Carers Australia, 2005. Available at http://www.carersaustralia.com.au/images/stories/Access%20Economics%20study%20full.pdf

AIHW *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

COAG Communiqué, February 10 2006, available at http://www.coag.gov.au/meetings/100206/index.htm

HDG Consulting Group *Acquired Brain Injury Slow to Recover Program Review: Final Report*, Department of Human Services, Victorian Government, Melbourne, November 2004.

Lansbury, R. & 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 Accessed June 1 2006.

Southern Health *ABI STR Program: Eligibility, Priority and Application*, August 2004.

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