Carrington Centennial Trust

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The Secretary
Senate Community Affairs References Committee
Suite S1 59
Parliament House
Canberra ACT 2600

Dear Sir/Madam

On behalf of the Board of Carrington Centennial Trust, I wish to make a submission to the Senate Inquiry into Aged Care. The submission mainly addresses the inquiry's term of reference C, that is: the appropriateness of young people with disabilities being accommodated in residential aged care facilities.

Carrington is a leading aged care provider in the Macarthur Region in South Western Sydney. It currently operates two (2) hostels of 50 beds and 74 beds, a nursing home of 94 beds, 194 self care retirement village units and provides community services to over 200 people per day.

Within the 94 high care residents there are ten (10) younger people with disabilities being accommodated in the aged care facility. There are five (5) people under the age of 33 years and the other five (5) are between 33 and 55 years of age. Recently we have prepared a briefing paper outlining the issues relating to the younger people with disabilities living in residential aged care facilities. The paper outlines the background and the care requirements of the young people with disabilities. It also outlines Carrington's proposalfor a model of care that would be appropriate for young people withdisabilities.

I attach a copy of the briefing paper to form part of this submission (Attachment A).

I also attached (Attachment B), a detailed casestudy about the care of "Stuart" a young disabled resident of Carrington. The case study gives a detailed account of the treatment/care management required by Stuart together with funding/cost issues relating to the current system of classification.

The Chairman of the Board and I would be happy to attend the inquiry and address the issues at a public hearing.

Yours sincerely

RAAD RICHARDS
Chief Executive

Carrington has been actively lobbying local, state and federal government to provide a new and improved system of care for people inappropriately housed in aged care facilities. Federal and State members have visited Carrington and have met with younger residents and management.

The Carrington Centennial Trust Board has made a commitment to provide capital funds to build a specific facility to accommodate younger people with high-care needs. This is an opportunity to provide an environment that optimises physical and cognitive function in these people. The recurrent funding responsibility for services for younger people with acquired brain injury is defined in the Commonwealth State Acquired Brain Injury Agreement (CSDA). The CSDA in each State defines the services to be provided by each party. Whilst the Commonwealth has primary responsibility for acquired brain injury employment services, advocacy and research, the State Governments have responsibility for accommodation services, as well as therapy, recreation and equipment. The CSDA is the instrument that governs the funding of all acquired brain injury services. For alternative accommodation places to be developed for young people, the State Government must provide funding under the auspice of the CSDA. Bureaucracy and politics hinder the decision making process regarding the ongoing recurrent funding for the operations of such facilities. Federal and State politicians have failed to negotiate a solution to this tremendously complex issue, in the hope that aged care providers will continue to accommodate young people who have an acquired brain injury in aged residential care under the current funding system. A system that fails to recognise the high costs associated with long term care for this cohort and the inappropriateness of the aged care environment for a young person, is a system that is inequitable and short sighted. It is becoming increasingly more difficult to place the young acquired brain injury resident into residential care. Many aged care facilities are refusing to accept these referrals.

The current alternative for people with high-care needs is community care. This may be in the family home or in a "group home". This care may be unsuitable due to the extreme pressure placed on family and carers. The provision of 24-hour nursing care by a family may be prohibitively expensive. The financial aspects of nursing care at home indicate a cost three times greater than a nursing home. This cost does not include the family's commitment to care which may be supported by a carer's pension.

Immediate care and rehabilitation-current practice

The service delivery of two local units, Liverpool Brain Injury Unit and Westmead Hospital Brain Injury Unit was examined. Both facilities offer specialist health services, that is, acute care (intensive care) followed by rehabilitation services, where the primary goals are to maximise self-determination, restore function and optimise lifestyle choices for acquired brain injury survivors. The rehabilitation process can vary in duration. It can be as long as two years if the patient is showing signs of improvement, or as little as months if a patient shows no signs of functional recovery.

Reintegration into the community for a person with a severe brain injury can be very difficult. Often this may require a program to support and promote independent living skills. This may involve post acute rehabilitation in an outpatient unit offering peer appropriate services, behaviour support, and life skill support. However, functional gains may be minimal and high-care support services are required.

Currently, some patients require assessment by an Aged Care Assessment Team for nursing home placement approval. The number of such patients is difficult to establish. The decision to place a young person with an acquired brain injury in a nursing home reflects the lack of alternative options.

Current Financial Implications

In a recent observational case study of a young person with an acquired brain injury living in Carrington, the Nurse Unit Manager was asked to compare the time and number of care staff required to deliver personalcare and physiotherapy care to the young person with that of a frail elderly person.

Activity	**Average time per day**
Meals – 20 minutes each meal	60 minutes
Drinks – 5 minutes x 6 daily	30 minutes
Washing/bathing/dressing/undressing/grooming x 2 nurses	60 minutes
Undressing and preparation for bed x 2 nurses	40 minutes
Changing pads per day x 3 x 2 nurses	60 minutes
Repositioning and pressure area care x 2 nurses	120 minutes
Planned evacuation of bowels 3rd daily x 2 nurses	10 minutes
Communication (extra time as speech is extremely slow)	20 minutes
Medications	15 minutes
Physiotherapy (passive range of movement exercises and stretches with nursing staff x 2 nurses	40 minutes
Physiotherapy one on one with Physiotherapist or physio aide 2hrs x 4days per week	70 minutes
Time spent with Allied Health, family management and others involved	10 minutes

This equates to a total of 8.9 hours per day and excludes diversional therapy. This total is significantly higher than the 5.1 hours of nursing care we would on average provide to a Category 1 frail aged resident.

The young acquired brain injury person was assessed as a Resident Classification Scale (RCS) Category 2, a category that attracts funding of $94.76 per day. The frail elderly resident was assessed as a Category 1 receiving $105.57 per day. Despite the younger person requiring more intensive type of care and therapies, the RCS fails to recognise this state of affairs.

In a breakdown of the Resident Classification Scale questions, the following data was collected:

- Maximum claim for therapies is a D in Question 19 (Therapy), which attracts a score of 7 if more than thirty minutes of therapy are provided three times per week. The young resident usually has two hours of Physiotherapy, in the Physiotherapy Department four times per week, and also receives passive range of movement exercises attended by nursing staff daily. Daily Speech Therapy occurs each day, as per the plan devised by the Speech Therapist, which equates to some 16.6 hrs per week. These therapies are crucial if the young acquired brain injury person is to continue to improve, and to prevent the complications that could develop if only given the maximum fundable amount of thirty minutes three times per week.
- Question 15 – Social and Human Needs – Care recipient - a D claim allows for 1:1 activity with the care recipient each day for thirty minutes. The young person with acquired brain injury gets much more than 30 mins daily, with organized music, computer use, and visits with other young residents (informally apart from any Diversional Therapy program). The maximum score that the D claim in this question attracts is 3.01. The reality is more than double the allocated time, and

there is no method to recoup the cost of these interventions.

- Question 16 relates to the Support given to family of a resident. Staff spend far more time on the phone, and in person with members of the younger person's family and friends, counseling, and supporting, than would be expected if a D claim is made, and the grand total of 0.91 is scored!

The resident has been living in Carrington Nursing Home for two years. In this time he has shown remarkable improvement in both physical and cognitive function. The provision of a slow recovery program has improved his quality of life as a result of improved function. However, what cannot be ignored is that the resource allocation to achieve this outcome is costly and inequitable. The service provider, and, indirectly, the frail elderly are compensating for the shortfall in funding. We also cannot ignore the fact that the young acquired brain injury resident is living with the frail elderly, people who have dementia, and those who are in the end stages of their life. The holistic aspects of wellbeing for this young resident are not fully and appropriately addressed.

A NEW MODEL OF CARE

There are two issues that need to be addressed:

1. The management of the needs of the young person with acquired brain injury who has "plateaued" and can no longer be provided with rehabilitation in a public hospital specialist unit. This person may benefit from slow progress rehabilitation over a 3-5 year period.
2. The management of the needs of the young person with acquired brain injury who has not exhibited potential to recover and requires high-care services, services that cannot be met in the broader community.

Carrington Centennial Trust proposes the development of a purpose built residential care facility with the provision of maintenance rehabilitation (Wilson

2004) for young persons with acquired brain injury. The intent is to provide an environment that meets both psychosocial and physiological obligations, and to assist the person, if they should improve, to transfer to a group home or to the family home.

It is acknowledged that many residents with acquired brain injury might not progress, despite slow progress rehabilitation, and might therefore require long term residential care with a maintenance program.

The current funding arrangements for residence in aged care facilities is not adequate for the long term care of young persons with acquired brain injury, as the RCS does not recognise rehabilitation efforts. Therefore, funding needs to reflect the intense resource allocation required to provide care and complex rehabilitation programs, such as speech pathology, physiotherapy, occupational therapy and psychology services.

Proposed Facility Profile

- 20-bed purpose built unit
- Treatment rooms and gym
- Offices for allied and specialist services
- Day care unit
- Bus and car access for community and visitor access
- Activity rooms for recreational activities

Staffing Ratio

- 1 fte RN per shift
- 2 fte AIN per 5 residents - AM shift
- 1½ AIN per 5 residents - PM shift
- 2 AIN on night shift
- 1 fte physiotherapist

- 2 fte physiotherapy assistants
- Part-time speech pathologist
- Part-time psychologist
- Part-time occupational therapist

Partnerships

- Community links with DSA and outreach programs
- Partnerships with Liverpool and Westmead Brain Injury Units
- Partnerships with SWSAH Rehabilitation Specialists (Camden)
- Partnerships with UWS
- Sports Council for the Disabled

Criteria for Entry

- ACAT assessment for Nursing Home approval
- <55 years of age
- Assessment by Carrington regarding suitability and care needs
- Confirmatory opinion from Brain Injury Rehabilitation Unit attesting to suitability for Carrington based on Glasgow Coma Scale, FIM (Functional Independence Measure) and other clinical measures.

Appendix

Brain Injury

Brain injury includes a complex group of medical and surgical problems that are caused by trauma to the head. Some of these problems result from a direct impact to a particular portion of the skull or brain. A skull fracture occurs when the bone of the skull cracks or breaks, and in a depressed skull fracture pieces of broken skull press into the brain. This can cause bruising of the brain tissue, called contusion. Other problems result from indirect mechanisms -- the stretching and tearing of blood vessels or white matter fibres, the "bouncing" of the brain against the inside of the skull or the secondary swelling of the brain due to injury-related chemical changes.

Damage to a major blood vessel within the head can cause a haematoma, or bleeding into or around the brain.

Severity can range from mild concussion to extreme coma or even death. A coma is a deep state of unconsciousness. Symptoms of brain injury may include loss of consciousness, dizziness, drowsiness, vomiting, headache, nausea, confusion or other cognitive problems. In the longerterm, difficulty with concentration and short-term memory, altered sleep patterns, a change in personality, depression, and other emotional and behavioural problems may become evident. Some people may have seizures as a result of brain injuries.

Although brain injuries can happen at any age- Forty per cent of brain injuries happen to people aged 17 to 25 and the cause is often a motor vehicle accident.

Treatment

Immediate treatment for brain injury may involve surgery to control bleeding in or around the brain, monitoring and controlling of pressure inside the head (intracranial pressure), other methods of ensuring blood flow to the brain, and treating the body for other injuries or infections. Seizures may need longterm anticonvulsant treatment.

Prognosis

The outcome of acquired brain injury depends on the cause of the injury and on the location, severity, and extent of neurological damage, and can range from full recovery to death. Long term consequences may include concentration problems, memory loss, personality and behaviour disorders, and speech and language impairment; these may result in loss of employment, lack of social opportunities, isolation and withdrawal and impaired family relations (Brain Injury Association of NSW, 2004 www.biansw.org.au)

Often after severe acquired brain injury where haemorrhage, hypoxia, and trauma have occurred, complications such as the following may ensue:

- Epilepsy within approximately 6 months, usually requiring longterm treatment.
- Swallowing difficulty
- Sialorrhea or drooling of saliva. This may reflect poor head posture and poor head movement control. A risk of aspiration of saliva may be present. Drooling may be treated with anticholinergic drugs, and with injection to salivary glands using botulinum toxin.
- Grinding of teeth
- Tremors. These may respond to drug treatment.
- Pressure sores.
- Heterotrophic ossification. This is abnormal bone formation particularly affecting the hips, knees, and shoulders. The problem may require physiotherapy, drug treatment, and even surgery.
- Infections, particularly of the urinary tract, chest, skin, and bone.
- Spasticity. This can result in difficulty in movement, abnormal movements and painful contractures.

12 May 2004

ATTACHMENT B

Case Study

To illustrate the complexity of management of a younger disabled person in an aged care setting, I will detail the care given to a current resident, Stuart.

Stuart was 26-year-old pedestrian who was hit by a truck on the 27 January 2000.

A CT scan revealed a severely fractured base of skull, cerebral oedema and multiple intra cerebral haemorrhages. Whilst in Liverpool ICU he suffered a series of complications including:

Raised intra cranial pressure
Respiratory failure
Hydrocephalus (excess fluid on the brain)
He began to have epileptic seizures
He developed bilateral knee effusions (water on the knees)
An enlarging right traumatic internal carotid artery aneurysm resulting in a major surgical emergency
Along with surgery for the evacuation of a large blood clot on the right parietal lobe of the brain
He developed diabeties insipidus (later resolved)
Developed vein clots in both internal jugulars and his subclavian vein (later resolved)
On three occasions he required to have a ventriculo-peritioneal shunt inserted to drain the ventricles of the brain through the neck, chest and abdomen and into the peritoneum to drain excess fluids

Stuart came to reside at Carrington in 31 October 2001 after being discharged from the Brain Injury Rehabilitation unit. Stuart had failed to progress and meet the set rehabilitation goals and hence it was time to move on the rationale being that although a person might still recover further, it is too slow to be taking up a bed in the Rehab Unit another case about sharing scarce resources and getting the best outcome for the health dollar unfortunately.

At the time he came to Carrington, Stuart was experiencing the following

- Did not have unassisted sitting balance
- Could not move any part of his body of his own accord
- Required a brace attached to his wheelchair to hold his head up for him
- Did not communicate as he had given up speaking/attempting to say anything.
- He received fluids/nutrition via a nasogastric tube.
- He was fully dependent for all daily living activities i.e. bathing, dressing, hair, nail, and mouth care.

So from his first day of admission our work began. He was assessed by our physiotherapist on the day after admission. Splints made up for his right hand and a roll for his left hand and a splinting program formulated for the application of ankle splints and positioning of pillows and other supports. (at Carrington we employ our own physiotherapist and physio aide)

We commenced a speech pathology and occupational therapy program with the assistance of staff from Liverpool Brain Injury Unit.

We commenced trials of oral pureed foods and at the instructions of the Speech therapist this could only be attended to by a registered nurse. It was naturally time consuming and required a great deal of encouragement to even get him to open his mouth a little.

However, a gastrostomy tube was inserted, as a more long-term solution was required for his nutritional and hydration needs.

His communication was by nodding or shaking his head if he responded at all.

Stuart also still suffered with allodynia (heightened sensitivity to pain) so a complex pain management plan was required. RN's also spent a great deal of time liasing with Allied Health Professions and other staff from the BIRU.

Staff also attended to daily physiotherapy with Stuart and continued the daily speech therapy exercise. Stuart had one on one time with our physiotherapist until June 2002 when he began daily sessions with the physio aide.

Stuart responded very well to this intensive input on a one to one basis. On the 15 October 2002 (nearly 12 months after admission) we had a breakthrough when he commenced communicating verbally again when he spoke his first two words….. and they were "BIG KEV". When he was asked what he meant he said, "EXCITED". Once he started there has been no stopping him…and a priceless and rewarding moment for staff was when he rang and surprised his mother. There was quiet a buzz around Carrington that day.

Stuart today:
Has unassisted sitting balance
Can move and raise his right leg, use his right hand and is practicing raising a spoon to his mouth.
Does not require a brace to hold up his head
Can communicate and is getting better every day
Receives his fluids and nutrition orally, eats normal meals
(Beer on special occasions)
and drives his finger controlled electric wheel chair around to the physio department by himself! This was only achieved in June2003!)

He recently dictated a letter to a friend where he tells him that he is learning how to drive his new electric wheelchair and he adds that so far he hasn't knocked out any walls or bowled over any old ladies.

Besides meeting the care and physical needs of our younger residents, it has also been our goal to improve the quality of lfe of our younger residents. Our Diversional therapists have weekly "youth" group activities including

Music afternoon
Movie afternoon
Board Games
Quizzes
Going to the Beach
Club
Shopping
Ten-pin bowling

As well as one on one activities such as:

Computer training including emails, letter writing
Speech therapy
Massage
Individual chats
Garden walks

Our younger residents also participate in the group activities with our other nursing home residents:

Craft
Cooking
Games
Exercise group
Entertainment
Sing alongs

Our younger residents are now also accessing programs being run by Disability Services Australia (DSA). (This has been another major breakthrough for us).

DSA run a number of programs including

- Programs offering 1:1 support for young people in Nursing Homes.
- Programs including cooking, swimming, woodwork, music therapy, Movies, BBQ's & picnics
- Most importantly if offers our residents the opportunity to Increase their network of friends.
- Eventually work experience opportunities.
- Network with vocational industries

DSA obtained very detailed information from client's familyand ourselves to ensure that it was able to cater for our residents' special needs or requests. In addition they have made sure that there was a social fit with the groupthey were being integrated into.

We have found this partnership with DSA to be invaluable to enriching the life of our younger residents.

So we are proud of our achievements with Stuart and he is only one of our residents who have made excellent progress whilst under our care. Whilst we believe that Carrington is giving and will continue to give excellent care to both the frail elderly and young residents, the downside is this care is being delivered at huge expense. The funding that we receive for younger residents is based on the Resident Classification Scale funding instrument (the infamous RCS) and is the instrument designed to assess and measure the needs of the frail elderly and not younger persons. The RCS is in fact designed to measure the multiple pathologies of elderly people (basicallylots of little problems associated with ageing where you can claim in every question). It does not capture the care needs of younger people, who have major deficits in particular areas.

Whilst the government has implemented a review of the RCS, the review does not intend to address any inadequacies the instrument might have in capturing the care needs of young people in nursing homes.

So whilst we continue to work hard with Stuart we have been rewarded by a drop in Category, ie he is now a Category 2.

The RCS is deficient in that

Even though Stuart has an Acquired Brain Injury with some frontal lobe damage, he does have insight and impulse control, and he is not disinhibited, so he has no behavioural problems. No claim can be made on any of the behavioural questions of the RCS where the potential maximum score is inexcess of 20 points and is often the case for the average nursing home resident.

The areas of greatest need for Stuart today to improve his quality of life are:
Physiotherapy,
Diversional Therapy,
Occupational Therapy and
Speech Therapy

The maximum claim for these therapies is a D in Question 19 (Therapy), which attracts a score of 7 if more than thirty minutes are provided three times per week. Stuart usually has two hours Physiotherapy, in the Physio Dept four times per week, and also has passive range of movement exercises attended by nursing staff daily, he also has Speech Therapy each day, as per the plan devised by the Speech therapist, which equate to some 16.6 hrs per week.

These therapies are crucial for Stuart to have any chance of improving his condition and preventing the complications that could develop if he was only given the max fundable of thirty minutes three times per week.

Question 15 – Social and Human Needs – Care recipient, a D claim allows for 1:1 activity with the care recipient each day for thirty minutes. Stuart needs, and gets much more than 30 mins daily, organizing his music, his computer, visits with other young residents (informally apart from any DT program). The max score that the D claim in this question attracts is 3.01 and like the Physio he has more than double the allocated time and there is nowhere to claim these interventions/time spent.

Question 16 relates to the Support given to family of a resident. Staff spend far more time on the phone, and in person with members of Stuart's family and his friends, counselling, supporting etc., than would be expected if a D claim is made and the grand total of .91 is scored!

An observational study undertaken by the Nurse Unit Manager who oversees Stuart's care has indicated that the average daily time for Stuart's care is as follows:

Activity	**Average time per day**
Meals – 20 minutes each meal	60 minutes
Drinks – 5 minutes x 6 daily	30 minutes
Washing/bathing/dressing/undressing/grooming x 2 nurses	60 minutes
Undressing and preparation for bed x 2 nurses	40 minutes
Changing pads per day x 3 x 2 nurses	60 minutes
Repositioning and pressure area care x2 nurses	120 minutes
Planned evacuation of bowels 3rd daily x 2 nurses	10 minutes
Communication (extra time as speech is extremely slow)	20 minutes
Medications	15 minutes
Physiotherapy (passive range of movement exercises and stretches with nursing staff x 2 nurses	40 minutes
Physiotherapy one on one with Physiotherapist or physio aide 2hrs x 4days per week	70 minutes
Time spent with Allied Health, family management and others involved	10 minutes

This equates to a total of 8.9 hours per day and is excluding diversional therapy.

This is significantly higher than the 5.1 hours of nursing care we would on average provide to a Category 1 frail aged resident.

Currently we have ten younger people in our facility and for us at Carrington it has become a question of balancing moral issues and financial pressures. We also have two people aged 25 and 38 who are on our waiting list for admission and who are pressuring us for a place.

As an organisation we have been actively lobbying government with our Local federal and state members visiting our facility and meeting with our younger residents.

The Carrington Board has made a commitment to provide capital funds to build a specific facility to accommodate younger people requiring the equivalent of nursing home care.

However, the recurrent funding responsibility for services for younger people with a disability is defined in the Commonwealth State Disability Agreement (CSDA). The CSDA in each state defines the services to be provided by each party. Whilst the commonwealth has primary responsibility for disability employment services, advocacy and research, the State Governments have responsibility for accommodation services, as well as therapy, recreation and equipment.

The CSDA is the instrument that governs the funding of all disability services. For alternative accommodation places to be developed for younger people they must be done under the auspice of the CSDA by the State Governments. They are caught in a bureaucratic and political funding trap and our stumbling block has been who will provide the ongoing recurrent funding for the operations of such a facility.

Federal and State Governments continue to play pass the parcel with a belief that if they ignore it for long enough it will just go away. I can assure you that Stuart and the other younger people we are caring for will not be going anywhere for a long time, as they are healthy and have a long life expectancy. It is therefore our collective responsibility to do something to improve the quality of life of these people.

We believe that Stuart and the others are on their own journey and we would like to think that Carrington is just a stopover.