Submission to the Senate Inquiry into Aged Care

This submission relates to Point C of the Terms of Reference of the Inquiry *'the appropriateness of young people with disabilities being accommodated in residential aged care facilities and the extent to which residents with special needs are met under the current funding arrangements'.*

Background

We are the relatives and friends of a young person with Acquired Brain Injury (ABI) who has languished in an Aged Care facility since his brain injury 8 years ago, surrounded by the smell of death and dying, dementia and other ailments of the frail elderly in God's waiting room. 13 men died in Chris Nolan's 4 bed ward in the first 4 years he lived there. He was emotionally overcome to know that his old 'mates' were dying around him.

This 28 year old young man Chris was a school captain versed in public speaking, great sportsperson, mentor to young people at risk (with a passion for social justice) and a solicitor working in Vietnam. After celebrating his birthday with a friend on May 28, 1996 he was discovered in bed comatose through a mystery illness and suffered a severe acquired brain injury.

Chris found himself emerging from the coma, hearing and understanding, though unable to move or speak and most people treating him as if he was 'not there'. Chris was eventually diagnosed as suffering from 'locked in syndrome' where his intellect is largely intact while he is trapped in a profoundly disabled body and communication system – he cannot speak, walk or move himself and is legally blind - this is a true mental prison.

A doctor at a public hospital where Chris spent 6 months said to Chris's parents "You are everyone's worst nightmare – it could be our son or daughter, or one of us"…brain injury can happen to anyone at any time.

Day to Day Reality

Chris has shown his true fighting spirit and has fought to stay alive even when the people around him almost thought that it was too hard to go on….for a long time there was no response at all from him.

He has now amazingly adapted to his situation and has found ways to communicate; blinking his eyes for 'yes', laughing at jokes and listening attentively to conversation for stimulation….he still despairs when his AFL footy team Richmond loses! With the assistance of his mother and carers he participates in the footy tipping competition at the nursing home and is about third in the competition.

Chris is still the same person with a great sense of humour who needs the same stimuli as other young people – his own music, listening to the football, to feel the wind in his hair and the rain on his face, to laugh and cry with his family and friends, to know what is going on in the world in terms of sport and politics etc.

It is essential to maintain and build his social network just as we all enjoy, however it is often difficult for us to visit him in an aged care facility as we feel restricted to being very quiet because he is surrounded by elderly patients and the environment is not conducive to that of a young person – light, airy, bright, loud music and buzzing with lively conversation.

Unless you are very outgoing like one of his young adult cousins who one day sang and danced for the four people in his ward ….much to the delight of Chris, patients and staff, it is difficult to maintain a 'normal' type atmosphere where natural conversation (albeit one sided) and silences flow.

Family and Friends striving for better conditions

We have seen enormous improvement in Chris over the years because he has been devotedly cared for particularly by his mother and father who have made huge sacrifices in their lives to achieve this. His father John Nolan is a farmer in Meredith which is 120 kms from Chris in a central Melbourne nursing home and travels every weekend to be with his only son and quite often sometimes during the week, at 64 this is taking its toll. His mother has chosen to be close to Chris and lives in Melbourne only returning to the farm at Meredith about once a month, spending her life being a voice for Chris and fighting for a better deal for him and other ABI sufferers.

They have purchased their own bus so that they can transport Chris to family and friends events such as weddings, christenings (Chris recently became a godfather), rock bands, football matches etc. and short stays at relatives at Christmas and home to the farm….where he can smell, hear and experience a familiar environment.

His wider family and professional friends have been a constant and continued support to Chris and his family so that together we strive for better conditions for these young people.

A group of mainly young people came together in 2001 to create a float led by three young people with ABI for the Victorian Federation Parade to highlight the plight of young people with ABI who require and have a right to high levels of care. This was the genesis of In**abi**lity Poss**abi**lity which became incorporated in September 2001. The name reflects that we all have inabilities and we all have possibilities. Melbourne based, Inability Possability is a volunteer organisation which seeks to address situations of disadvantage experienced by these young people.

Several projects have been undertaken to increase awareness of the isolation and reality experienced by young people with ABI and their families. Many are regarded by the community and medical profession to be 'vegetative' when in fact they can improve just like Chris with the right stimulation in the right environment. This led to Inability Possability initiating a meeting of these young people, their families, friends and carers in January 2002 which in turn resulted in the formation of a Family and Friends Association. The association includes young people many of whom live in nursing homes, are cared for at home or are awaiting placement in an acute care facility. Contact has been made with over 80 people including 30 young people with ABI.

In May 2002 there was a National Summit on Young People in Nursing Homes (YPINH), Inability Possability decided to use story or biography as a means to give some 'voice' to the young people with severe ABI. Many of these people are unable to speak for themselves. Much has been achieved in raising awareness of the issue of young people with ABI since Inability Possability's inception, including participation in a National Summit of Young People in Nursing Homes in 2002 and National Conference on the issue in 2003.

Inability Possability's second edition of 'still the doors are open – writing of life' is the voice of these marginalised young people and they summarise their plight –
'The isolation and lack of understanding experienced by this group is overwhelming. Most friendship groups disappear after their injury, because of its confronting nature. We would like to honour and pay tribute to the courage, struggle and inspiration of young people with ABI and their family and friends'.

It is interesting to note that Mary Nolan, Chris's mother and member of Inability Possability received a commendation in the Community Section of the Human Rights Awards for her work in the area of young people with ABI in December 2002. She has been invited to give the key note address at many conferences and it has been said by health professionals that she leads the way with her innovative and collaborative approach, which is a first for Australia and maybe the world.

A Plea to Government for Help

"Everyone has the right to recognition everywhere as a person"
Article 6, Universal Declaration of Human Rights

Often the staff in nursing homes are not adequately funded or trained to care for young ABI victims who subsequently experience extreme suffering and isolation. One recent example in Melbourne was one of Chris's young ABI friends James who wasted away in a bright and shining relatively new nursing home with substandard care and was buried in mid 2004.

A mother Carol walked into the nursing home to find her son in a darkened room on a beautiful sunny day sweating profusely, grunting and moaning because his body was so distorted and he was incapable of moving a limb, let alone turn his body to a position that would be half comfortable. To know that he may have been like this for hours causes such anguish, to reel from the smell of urine and excrement and know that he has been subjected to the indignity of laying in it for hours.

These young people can’t use a buzzer, can’t shout out for attention and yes, we know that nursing homes are understaffed and aren’t really set up for high maintenance care for these ABI patients but does that really explain the missed peg feeds, the discarded dressings on the floor, the lack of cleanliness in the room or the horrendous bed sores that sometimes never heal. **This is the cry for help of some of the most marginalised in our society today.**

Chris’s subsequent misfortune is that he did not sustain his brain injury in a car accident, in which case he would have been adequately covered by Transport Accident Commission funding and placed in appropriate accommodation with a range of rehabilitation therapies, appropriate for a young person with such an injury. This highlights the further marginalisation and injustice towards Chris and those who suffer a similar plight because of the cruel twist of fate of how they sustained their injury.

Life pathways for young ABI people lead into nursing home care but there are none to exit back to life (Dr. Joan Tierney, Melbourne GP).

We ask that consideration by the Commonwealth government is given to a pilot that provides a ***pathway back to life*** for some of these young ABI people currently languishing in nursing homes.

A purpose built facility as a pilot is desperately needed to look at new models for young ABI people’s care…..it is not working lumping them in aged care facilities causing desperation for the young ABI person and considerable stress for the staff and families. We need to dare to dream how much better these young people’s lives could be if we just took the time to create a vision for a better future.

This could be a multi disciplinary model where the capital work funds for the building are provided through philanthropic trusts, recurrent funding is provided by government for operational functions and ongoing therapy etc. and the facility is integrated into the community with support services provided by existing volunteer community groups and local agencies. The social support is provided by family and friends and associated networks.

As Chris’s nursing home is closing down within two years and the alternative he has been offered is a considerable distance from central Melbourne he is in risk of losing his social network because of inaccessability coupled with the heartbreak of his parents struggling to travel to his new ‘home’.

There is a group of Chris’s family and friends, Inability Possability and associated professionals currently working on this integrated model for a pilot. The central city Melbourne site of Chris’s current Nursing Home will be redeveloped possibly for young homeless people in two years. This is a great opportunity to approach the not for profit organisation who lease the site or to look at alternative central Melbourne sites for a pilot facility to address the needs of perhaps the most marginalised of all – young ABI people with no voice.

There are approximately 16 people with ABI under 40 yrs of age currently inappropriately accommodated in nursing homes in Victoria – there is a solution to this problem to prevent further suffering.

However this will need recognition and funding from the Commonwealth Government and we ask that the Senate Committee consider our request to assist us in creating a new visionary model of integrated care for young ABI people in Victoria, through the establishment of a pilot facility.

'We are deeply affected by the thought of people buried alive under collapsed buildings or earth and go to great lengths to get them out……..
….can we do less for these young people?' (Inability Possability Incorporated 2004).

Signatory **Noreen Nicholson**

I request a chance to give evidence at a public hearing if the opportunity arises. *Noreen Nicholson*

Co-signatories:

Bill Nicholson
Anna Nicholson
Peter Nicholson
John Gleeson
Noellene Gleeson
Mary Martin
Anna Munari
Anthony Conlan
Ben Jordan
Peter Webb
Brenda Webb
Leonie Rastas
Helen Nolan
Andrew Nolan
Marcus Nolan
Jane Clark
David Nicholson
Anne Kavenagh
Sue Brown
Sally Di Martino
Sue Robertson