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Young people in nursing homes

White Paper

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Abbreviations

ABI	Acquired brain injury
ABI:STR	Acquired Brain Injury: Slow to Recover
COAG	Council of Australian Governments
DHS	Victorian Government Department of Human Services
FaHCSIA	Australian Government Department of Families, Housing, Community Services and Indigenous Affairs
MS	Multiple Sclerosis
RAC	Residential aged care
SSA	Shared supported accommodation
YPIRAC	Younger people in residential aged care

Aim

The objective of this white paper is to summarise the research and policy context related to the issue of young people in nursing homes in Australia.

This discussion paper aims to:

- summarise research regarding the social inclusion of young people in nursing homes
- provide background on the policy and practical challenges regarding young people in nursing homes.

Executive Summary

An estimated 3300 people under the age of 60 live in nursing homes, which are not suited to their needs¹. Aged care facilities are not designed or resourced to facilitate the active involvement of young people with high clinical needs in everyday activities or support their continued participation in the life of their community²⁻⁵.

Young people in nursing homes are one of the most marginalised and isolated groups of people in our society, with 53% receiving a visit from a friend less than once per year and 82% seldom or never visiting their friends. They are effectively excluded from our society.

The five-year \$244 million national Young People in Residential Aged Care (YPIRAC) program concluded in June 2011. This program made a significant difference to the lives of hundreds of people with a disability.

Although the initiative was a great start, it will not result in the long-term reduction of young people in residential aged care (RAC)²³. In 2006, this initiative was presented as a “first step”⁷. Developing the scale and range of accommodation options required to resolve the issue of young people living in or at risk of admission to RAC will require a whole-of-government approach with the housing, health and disability sectors working in partnership.

What is the issue?

There are many young Australians stuck in nursing homes. This is a serious social issue, which can – and must – be fixed. An estimated 3300 people under the age of 60 live in nursing homes, which are not suited to their needs ¹.

These aged care facilities are not designed or resourced to facilitate the active involvement of young people with high clinical needs in everyday activities or support their continued participation in the life of their community ²⁻⁵.

Rather, nursing homes are designed to provide accommodation, personal and nursing care to frail older people at the end stage of their life with the average age of residents in aged care facilities being 83 years ⁸.

Young people with disability living in nursing homes are one of the most marginalised and isolated groups of people in our society. They generally lead impoverished lives, characterised by loneliness and boredom. A Victorian study of 330 residents under 60 years found that young people in nursing homes:

- experience increased levels of social isolation from peers (44% receiving a visit from a friend less than once per year)
- have limited community access (21% went outside seldom or never)
- have reduced opportunity to participate in community-based activities such as shopping, leisure activities, or visiting friends and family (34% almost never participated) ⁹.

In 2002 the Victorian Government released the State Disability Services Plan 2002 – 2012 that stated “people with a disability should be able to choose where they live, with whom and in what type of housing—just like most other members of the Victorian community” (Department of Human Services, 2002, p.13). In July 2008, the Australian Government ratified the United Nations Convention on the Rights of Persons with Disabilities (CRDP). Article 19 of the United Nations CRDP says that all people with a disability have a right to live in the community. The convention stipulates that people with a disability should have the “opportunity to choose their residence and where and with whom they live on an equal basis with others, and not be obliged to live in particular living arrangements” ^{10, p. 13}. This convention also states that people with disability should have a “range of in-home, residential and other community support services including personal assistance...to support living and inclusion in the community, and to prevent isolation or segregation from the community” ^{10, p. 14}.

However, there is a disconnection between the policy aspirations outlined in the State Plan and the UN’s CRDP and the lived experience of people with disabilities (Department of Families Housing Community Services and Indigenous Affairs, 2009a). The disability service system simply has not been allocated the resources necessary to support people with disabilities to

attain the level of choice and social inclusion articulated in the state plan (Bigby & Fyffe, 2008). In reality, people with disabilities with high care and complex care needs who do not have access to compensation have very little, if any choice about where they live, whom they live with or the type of support they receive.

The disability service sector in Australia has been described as under-resourced, highly rationed and fragmented ¹¹⁻¹³. This environment does not foster the innovation and collaboration required to achieve the social inclusion of people with disability. Central to bringing people with disability back into the mainstream of society is providing a stable living environment, and moving away from the entrenched crisis responses to addressing their accommodation, services and support needs ¹⁴.

How do young people end up in nursing homes?

Improved medical technology and rehabilitation have increased the survival rates and life expectancy of people with severe acquired brain injury (ABI) who have concurrent complex care needs ¹⁵. People who sustain a very severe ABI, who once would have died at the scene of the accident or in hospital are now surviving ¹⁶.

People also live longer with degenerative diseases such as multiple sclerosis ¹⁷. This has resulted in a new population of people with severe disabilities and complex care needs that require 24-hour supervision or very high levels of daily care and support, challenging the established disability service system.

Hospitals are the most frequent source (59%) of admission to RAC and home settings are the least frequent ^{4, 18}. One recent study found that some (18%) were in hospital for more than six months prior to their placement in the nursing home ⁴. This suggests that disability services need to partner with health services to develop pathways from acute and rehabilitation hospitals to community living in order to reduce/prevent new admissions.

What are the characteristics of young people in nursing homes?

Disability types

Young people in nursing homes have a range of disability types:

- 58% have an ABI
- 13% multiple sclerosis
- 9% Huntington's disease ¹⁹.

What is acquired brain injury?

Acquired brain injury (ABI) refers to any damage to the brain that occurred after birth. Common causes of ABI include accidents, assaults/attacks, falling from heights or diving into shallow water, episodes which have deprived the brain of oxygen (e.g. severe asthma attacks) and stroke.

ABI-related disability can affect cognitive, physical, emotional and independent functioning (<http://www.brainlink.org.au>).

What is Multiple sclerosis?

Multiple sclerosis (MS) is a disease that affects the central nervous system and can, to varying degrees, interfere with the transmission of nerve impulses throughout the brain, spinal cord and optic nerves. MS can progress in different ways. Some people with MS may become seriously disabled. Others may have one or two attacks and then remain symptom free for the rest of their lives (<http://www.msaustralia.org.au>).

What is Huntington's disease?

Huntington's disease is an inherited, neurological disorder causing gradual deterioration of physical, cognitive and emotional abilities. It is primarily a disease that affects adults, usually appearing between the ages of 30 and 50 (<http://www.ahda.com.au>).

Support Needs

Young people in nursing homes are a diverse group with a complex range of health and support needs that are not adequately met within the nursing home environment. Many people (37%) require the highest level of support, indicating they cannot be left alone while 26% can be left for part of the day and overnight ¹⁹.

Some common misconceptions

Generally, people need to be over 65 years to be eligible for residential aged care services in Australia.

Under the Aged Care Act, people younger than 65 with disability are able to enter nursing homes if they are assessed as needing the intensity, type and model of care provided in such facilities, and provided no other more appropriate service is available ²⁰.

Young people are not necessarily placed in nursing homes because they require 24-hour nursing care (although they may require 24-hour supervision and assistance); it is usually because there are no practical or viable alternatives ²¹.

Young people with very high care needs living in nursing homes have, potentially, many years of life ahead of them. However, some people in this population have been described as having a 'narrow margin of health' ²². This means that they are highly susceptible to secondary conditions that can make them critically ill or result in premature death.

There is a common misconception that young people with complex care needs are 'safer' in nursing homes where they have access to 24 hour nursing care. However, a Victorian Government Department of Human Services report found that between July 1999 and June 2005, 150 people under 50 living in nursing homes died, with an average of 21.4 deaths per year ²³.

During the same time period, a further 101 people had 'other reasons' for permanent discharge, including discharge to an acute hospital. It is probable that death was the outcome in some of these instances. Degenerative conditions and cancer are likely to account for some of these deaths; however a recent study found that less than 28% of people under 60 years in nursing homes had a degenerative condition such as Huntington's disease and only 1% had cancer ⁹.

Given the relatively small incidence, these conditions alone do not account for the high rate of death. Given the frequency of falls and hospital admissions, and the high death rate, it appears that nursing homes do not provide the level of support required to manage the health care needs of young people with disability. Many of the episodes of illness and the resultant hospital admissions experienced by young people in nursing homes appear to be predictable and preventable ¹⁹.

The current service system

The current service system for Australians with an ABI is inequitable. There are two systems in place depending on how you are injured and what state or territory you are in. Those who sustain their brain injury in a car or at work often have access to rehabilitation and lifetime support. While those who have an aneurysm, stroke, near drowning, severe asthma attack, assault or drug overdose are dependent on publically funded health, rehabilitation and disability services.

The Victorian context

In Victoria over the past two decades there has been a widespread development of community-based services to replace institutions. A vibrant non-government sector has emerged to provide services and advocate for continual service development. Victoria has been leading other states in policy and pilot programs related to individualised planning and funding. The non-government sector has also been advocating for change and the development of alternatives specifically for young people living in aged care for many years. Initially services were largely developed for people with compensation (funded by the Transport Accident Commission or WorkCover). More recent advocacy and service development has focused on people without compensation.

The Transport Accident Commission (TAC) delivers a personal injury scheme that provides needs-based no-fault benefits for medical, rehabilitation and disability services. The TAC has been proactive in funding and working with community service providers to develop alternative accommodation options over the last two decades for clients with neurotrauma. The TAC is currently funding more than 100 clients to live in shared supported accommodation options throughout Victoria. Many more people funded by TAC live in a wide range of individualised accommodation settings. Prior to the recent YPIRAC initiative, there were already more than 40 shared supported accommodation facilities developed specifically for people with ABI in Victoria.

A recent study compared 128 people with ABI living in shared supported accommodation (SSA) in the community with 61 young people with ABI living in nursing homes in Victoria³. SSA is a home-like environment generally for 4-6 people who share support provided by disability support workers. Most of these facilities provide 24-hour care with either active or inactive overnight support.

Most of the places for people with ABI living in SSA were funded by the Transport Accident Commission. Residents financially supported by the TAC also have access to approximately eight hours per week of individual attendant care for community access and availability of allied health services such as nursing, physiotherapy, occupational therapy and speech pathology.

The study found that the two groups had a similar level of disability. However, compared to those in nursing homes, the people living in group homes went outside more often, accessed

the community more often, participated more often in community-based leisure activities and visited friends and family more often.

The Acquired Brain Injury: Slow to Recover (ABI:STR) program, unique to Australia, was established in 1996 for people with catastrophic brain injuries who were not eligible for compensation or who were not accepted into traditional rehabilitation services. The ABI:STR program is a Victoria-wide program that is managed by Southern Health. This program provides individually targeted slow-stream rehabilitation services to people to maximise their potential to achieve functional gains and thereby to assist them to achieve optimum levels of independent functioning. Approximately 23% of people under 50 living in residential aged care (RAC) in Victoria receive services funded by the ABI:STR program ²⁴.

The flexible support provided by this program has enabled a limited number of young people with ABI to move from RAC and return to community living ²⁴. However, the lack of affordable supported accommodation for people with ABI who have high care needs has been a barrier to many people funded by the ABI:STR program returning to community living. The ABI:STR program funds therapy and disability supports related to rehabilitation goals but it does not fund supported accommodation. There are also a significant number of people who are at risk of admission to RAC who are not eligible for the ABI:STR program. For example, people with neurodegenerative conditions and people with an ABI that is not related to an acute health episode within the preceding two years are excluded from this program.

Four Case Studies

1 | Angela Barker

Angela (Anj) was an active 16 year-old when her life changed in a split-second, and she and her family were confronted with the idea of Anj living in a nursing home for the rest of her life. The week Anj had commenced practising for her debutante her life changed forever when she was brutally bashed to near-death by her ex-boyfriend.

Anj survived the bashing but suffered a severe brain injury. Initially she was rushed to hospital then urgently transferred to Melbourne. There she lay unconscious for 2 months. She spent then next two and a half years living in a nursing home. Anj describes this not as living but as “hell.” She felt angry, trapped and incredibly sad that this was her life. Her parents made the brave move to bring her home, and together with her carers, provide the everyday care and help Anj needs.

Her determination and strength have enabled Anj to keep moving forward despite the horrific injuries she suffered, and the medical concerns that she would not improve. She describes how “with the help of my family and friends I’ve been able to keep soldering on.” This ‘soldering on’ kept her alive, helped her survive living in the nursing home, helped her leave the home to return to her family.

Anj is a determined young woman and is not only a survivor but has chosen to open the hearts and minds of others. She campaigns and educates the public on anti-violence. She gives talks to students, young women, to police and even to politicians. Anj empowers others to say no to violence, and has represented Australia at the United Nations level. She helps educate others to overcome their barrier to see the person not the disability. In addition she advocates, speaks, and writes to help stop young people ending up in nursing homes.

In recognition of her inspirational work, Anj was recently awarded the title of Victoria’s Young Australian of the Year for 2011.

Anj recently took a big step toward the independence she is striving for, by moving out of her family home to a unit in Melbourne, a place she can call home. Anj is now focused on achieving as much independence as possible in her new home.

At the thought of returning to a nursing home Anj says “we, young people, still deserve every chance to live a full life, give it our best and not be given a life sentence and be left to live with those who are dying...”



2 | Jason Anderson

Jason Anderson grew up in Melbourne's east, and describes his family as 'unremarkable.' His Dad worked for the Roads Corporation and his Mum stayed at home and did other people's laundry for a bit of extra cash, while Jason's passion for the Monaro played out in backyard suburbia. At 24, when his daughter was four months old Jason was attempting to get his motorcycle licence when he noticed that his balance wasn't good. A visit to his GP and then a neurologist led to a formal diagnosis of multiple sclerosis.



"There were lots of stresses from the very beginning, it was a real struggle – we had a split level house which we needed to modify – put in a lift, ramps outside, a wider door on my workshop. Our bedroom was downstairs and I moved upstairs – there were no services, we had to get philanthropic funds to assist with building modifications. The council sent a worker who was too old to lift me. Rita had to do everything. Almost overnight she had become my carer, (you can't cross that line) and the breadwinner, she hurt herself lifting me – we got our money's worth out of the ambulance service who we called for help whenever I had a fall.

"We managed for 13 years without any help from anyone. We were just trying to be normal. We did not get a pension. I was the house parent. [The kids] knew no different. I would take them to school on the scooter in the morning – pick them up in the afternoon and look after them until Rita got home from work. Our paths were altered and it happened really quickly – things like modifications took ages to get so you always needed to plan ahead – its like being a rain calibrator – you don't know if its going to rain and if it does you don't know how much it will rain – there is much uncertainty."

After 12 years Jason says that the marriage succumbed to the pressure and the couple separated. "I tried so hard to be a good husband. I tried to stay out of this chair, but this disease was too strong. I felt beaten, I felt worthless, I felt helpless."

Now in his early 40's living in picturesque Williamstown, Jason reflects on his past. There is a sense that then, as now, his persistence, optimism, courage and desire to do normal things has him well and truly back on track. He has studied, completing the Leadership Plus Program, is the face of the MS Society and a Building Better Lives Ambassador. Jason is also keen to see the implementation of a National Disability Insurance Scheme (NDIS):

"If the NDIS had existed when I was first diagnosed with multiple sclerosis I would not have had to wait and save up for home renovations or equipment. I would have received personal care support, which would have helped ease the pressure and stress on me and my young family. I would have also received therapy much earlier - maybe it could have helped me stay in a job, maybe it could have somehow helped delay the progress of my disability. What this scheme would mean for me now is that I would be more independent, I could choose where to live, who I live with, and also have a place where my kids could stay over - that would mean everything to me."

3 | Michelle Newland

With the world at her feet, Michelle Newland had completed the first year of her primary teaching degree – finishing in the top 10% students at Australian Catholic University when just three days after celebrating her 19th birthday, she suffered a near-fatal asthma attack which resulted in a severe brain injury.

Michelle's journey of recovery has been long and arduous – a credit to her hard work and tenacity. Michelle's rehabilitation has been greatly enhanced by the fierce love and determination of her family, friends and carers. Michelle has had to relearn everything – the only capacity unaffected by Michelle's brain injury was her ability to hear. Michelle's mother Ann articulates the enormity of Michelle's rehabilitation by pointing out "Michelle has had to relearn everything without the benefit of instinct which babies possess."

For six years following her ABI Michelle received her nutrition in a liquid form via a PEG tube inserted directly into her stomach. Only recently has Michelle mastered the art of swallowing to the point that she can again consume food and drink through her mouth.

In addition to battling gruelling physical rehabilitation in the areas of speech, gross and fine motor movement etc, Michelle continues to struggle with both short-term memory loss and Amnesia. In the years immediately following her brain injury Michelle was frequently unable to recognise those closest to her, including her own parents.

Michelle's family regard her Amnesia as a blessing on many levels, as they recount the time Michelle spent in a nursing home, lying in bed surrounded by people significantly older than her, where visits from friends were not encouraged and the progress Michelle had made in rehabilitation prior to entering the nursing home, slipped dramatically backwards. At this point Ann and her husband knew that whatever it took, they had to bring their daughter home.

Michelle demonstrates the potential of people with an ABI and the value of investing in their development. Through her hard work and the tenacity and support of her parents, Michelle has regained her continence, re-learned to talk, swallow, read, dress, walk and swim. She would never have realised her potential languishing in a nursing home and she hasn't finished yet. Through all this Michelle remains positive and focused. Michelle is rightly very proud of her progress and regards herself as "Blessed."

Today Michelle has established a name for herself making greeting cards in her local community. She also spends two days a week volunteering at her local primary school, the same school she once attended. Michelle says, "young people just don't belong in nursing homes, it is not the right environment and young people need to be surrounded by people of their own age."



4 | Grayden Moore

At 23 years of age, Grayden Moore was on the brink of his adult life – and what a life! Grayden had just returned home from Florida after completing a degree in Sports Management, and was ranked in the top 10 junior tennis players in Australia. He leapt back into his fast-paced, action-packed life. He surfed, he played football, he coached junior tennis, socialised, partied, loved going to the beach ... and he rode his skateboard . . .



It was a devastating skateboard accident that abruptly, dramatically and permanently changed the course of Grayden's life. If not for the immediate response of the neighbour who witnessed the accident, Grayden's story would have ended that October day in 2004. The journey Grayden and his family have faced since the accident has been arduous. For a long time Grayden's grasp on life was tenuous, and his recovery suffered major set backs along the way. Backed by a strong, supportive and proactive family, Grayden has made significant progress.

Grayden says with pride "it is miraculous to recover from the critical condition I was in, and defy the odds, and every doctor's opinion regarding my outcome and future..... I was sent to a nursing home where I was with people more than twice my age. I would love to meet the doctors who initially saw me who said I would remain a vegetable for life and never be able to talk or walk – if I didn't die."

Grayden's accident effectively erased his memory for eight years of the life he lead – the dynamic, successful six years prior to his accident largely spent studying and touring on the international tennis circuit, and the first two gruelling years of recovery following the accident. Slowly, snippets of memory are returning, but he relies on his family to fill in the gaps.

Grayden has had to relearn the most basic functions – it was 2006 before Grayden was able to sit by himself and begin the process of learning to walk again. Piece-by-piece Grayden is reconstructing his life – touching those he meets along the way with his gentle nature, his sense of humour and his passion for life.

"My philosophy since the accident is to remain positive and live the remainder of my life as though I'm looking through the windscreen, not the rear-vision mirror."

Grayden actively lends his support and voice to a cause close to his heart — keeping young people out of nursing homes. He himself has recently moved into a supported accommodation unit, where he is surrounded by other young people, and where he can live his life as independently as possible: "every young person should be in a place they want to live in with the support to be as independent as possible.... every young person should have this choice."

What are the State and Federal governments doing?

National Young People in Residential Aged Care (YPIRAC) program

At its February 2006 meeting, the Council of Australian Governments (COAG) agreed that the Australian Government, state and territories would, from July 2006, work together to reduce the number of young people with disability living in aged care. Governments jointly established and funded a \$244 million five-year national Younger People in Residential Aged Care (YPIRAC) program, with the initial priority being people aged under 50.

The initiative aimed to move 689 people out of nursing homes by July 2011. As at 30 June 2010, only 139 people in residential aged care had moved to alternative accommodation.

A recent study found that not enough accommodation and support options have been developed in this initiative to meet the current needs of all the young people living in nursing homes or at risk of admission, let alone meet future demand ⁶.

Young people in nursing homes have a diverse range of support needs and preferences for accommodation and support. However, the YPIRAC program has not developed the variety of accommodation and support options required to support the wide range of individual needs and lifestyles ⁶. Most of the services being developed are group home or congregate care models where people have no real choice in where they live, or with whom they live ⁶. The limited range of options developed in the YPIRAC initiative is out of step with the policy aspirations in the disability sector, which focus on person-centred planning and state that people with a disability should be able to choose where they live, with whom, and in what type of housing ^{10, 25}.

A recent study also identified the need for the health and disability sectors to develop and jointly fund new services to create pathways out of hospital for the YPIRAC target group. These services would give young people at risk of admission to RAC the time and services they require to recover and maximise their abilities ^{19, 26, 27}. They also have the potential to reduce further admissions to RAC, reduce the costs of lifetime care and make better use of resources available for disability supports ^{19, 26, 28}. One of the key findings from this study was the importance of preventing new admissions to RAC facilities rather than moving people out to community settings after they have been admitted.

The five-year \$244 million national YPIRAC program has made a significant difference to the lives of hundreds of people. However 621 people under 50 remain in nursing homes throughout Australia and more than 200 are likely to be admitted each year.

There are two key factors that need to be addressed to significantly reduce the number of young people in RAC in Australia. Firstly, there needs to be a dramatic increase in both the

range and number of supported housing options. Secondly, there needs to be systemic change to stem the flow of young people into RAC facilities.

Although the current initiative is a great start, it will not result in the long-term reduction of young people in RAC²³. In 2006, this initiative was presented as a “first step”⁷. Developing the scale and range of accommodation options required to resolve the issue of young people living in or at risk of admission to RAC will require a whole-of-government approach with the housing, health and disability sectors working in partnership.

Victoria’s my future my choice program

In Victoria the YPIRAC program was called *my future my choice*. In 2006, the Summer Foundation was appointed by the Victorian Government Department of Human Services (DHS) Disability Services to develop an assessment and planning framework for *my future my choice* and aggregate the data from the planning process. In December 2007 the Summer Foundation produced a report called *Younger people in residential aged care: Support needs, preferences and future directions*. This report was used by DHS Disability Services to plan systemic change and develop services to meet the needs of young people in nursing homes.

The targets for the five-year initiative agreed between the state and federal governments included:

- Net reduction of between 71 and 136 people under 50 years living in aged care
- 140 people to move out of aged care
- 60 people to be diverted from admission to aged care
- 40 people to receive enhancement packages.

The recent *my future my choice* program has developed 22 new services in Victoria that will accommodate 104 people who are either living in aged care or at risk of admission. In addition to creating these new services the program has provided 70 enhancement packages to young people who remain in nursing homes because they either chose to remain in a nursing home or no alternative was available. These support packages have been used to increase participation in the community, support family and friendship contact, provide therapy and purchase important aids or pieces of equipment. This program has provided disability supports to enable 50 young people to return to community living. At the start of the program in July 2006 there were 221 young people (under 50) living in nursing homes in Victoria. In April 2011, this number stood at 126.

People who are currently receiving services through the *my future my choice* program will continue to receive these disability supports although the initiative has come to an end. However, given that 126 people remain in aged care, the program has not met current demand let alone future demand. There are also people in their early fifties who have significant potential but remain in aged care. There will be no new packages for the 70-80 people under 50 who are admitted to aged care each year in Victoria. Without sustained investment in new accommodation options, young people in nursing homes will once again be lost in the gaps between health, disability and aged care.

In April 2010 the Summer Foundation was appointed by the DHS Disability Services to undertake a Quality of Life Evaluation for individuals participating in the Younger People in Residential Aged Care *my future my choice* initiative in Victoria. Over a 12-month period, participants and their families will be interviewed to assess whether there has been an improvement in the quality of life since moving out of (or being diverted from) a nursing home, and identify factors that foster or impede successful outcomes to inform future service delivery. The final report for this evaluation is due in January 2012.

The number of people under 50 in Victoria may have reduced from 221 to 126 during this five-year program. However, without a commitment to renew this program that has changed the lives of so many, these numbers will steadily climb over the next 5 years and return to 220 people under 50 in nursing homes in Victoria. This was the Western Australian experience following the conclusion of the Young People in Nursing Homes Project that commenced in 1995 and moved 95 young people with a range of disabilities from RAC to community-based living (Jones & Lawn, 1999).

Productivity Commission Focus on Disability

In November 2009, the Productivity Commission was appointed by the Australian Government to look at the feasibility of a no-fault social insurance scheme for people with severe or profound disability. This welcome inquiry will look into the costs, benefits and feasibility of approaches that provide essential care and support. The inquiry began in early 2010 and will report by to the government by July 2011 ²⁹. The National Disability Insurance Scheme offers some hope for young people in nursing homes. It has the potential to provide the resources that this group need to remain living in the community. However, this program will not be implemented until 2015-2018.

The proposed National Disability Insurance Scheme will provide recurrent funding for support including speech, occupational and physio therapies, disability supports and case management. However, the introduction of this scheme alone will not bring young people in nursing homes back into the mainstream of society, it is essential but only part of the solution. There exists and will be an ongoing need for a greater range and number of alternative accommodation options, services that create pathways to community living and community based supports that are flexible and responsive to changing needs to keep young people out of nursing homes. It is this critical work that the Summer Foundation and other organisations need to undertake pending the introduction of a no fault insurance scheme.

What next?

Without a continuing commitment from the state and federal governments to the national Younger People in Residential Aged Care program, this initiative is unlikely to achieve any long-term impact. Each year more than 250 people under the age of 50 across Australia will enter nursing homes and be forgotten.

As outlined earlier, there are two key factors that need to be addressed to significantly reduce the number of young people in RAC in Australia. There needs to be systemic change to stem the flow of young people into RAC facilities. There also needs to be a dramatic increase in both the range and number of supported housing options.

Prevention of new admissions

There is one new service currently being considered by the Victorian State Government that has the potential to significantly reduce the new admissions of young people with ABI to nursing homes. Southern Health has been asked by the Victorian Department of Health to commence planning for a new state-wide, slow-stream rehabilitation ABI service. Caulfield Hospital has conducted consultation forums to begin to develop the model of care. This new service has the potential to significantly reduce the number of admissions to aged care by giving people the time and rehabilitation required to maximise their potential so that they can return to community living with support. Similar facility based slow-stream rehabilitation ABI services are required in each state and territory of Australia in addition to community based slow-stream rehabilitation ABI services in order to reduce the new admissions of young people to nursing homes. Although these service will assist to divert young people from being admitted to aged care, they will only be successful if there is also an increase in the number and range of supported accommodation options at the end of the rehabilitation process.

Sustained investment in alternative accommodation options

There needs to be sustained investment to extend the range and number of accommodation options available to young people in nursing homes. People need a variety of alternatives to meet their individual needs and to enable them to have a real choice. The disability sector needs to develop and evaluate a range of accommodation and support options for this target group.

About the Summer Foundation

Established in 2006, the Summer Foundation aims to resolve the issue of young people living in nursing homes. The foundation has adopted a social inclusion framework to address the multiple disadvantages experienced by young people in this target group, and utilises a range of strategies to influence health, housing and disability services policy and practice. These strategies are depicted in the figure below. The Summer Foundation is not able to implement all of these strategies in isolation; it collaborates with other organisations and government to create positive change.



Creating a movement

Supporting people with disability to provide leadership to existing stakeholders and engage the corporate sector and general public

Empowering

Enabling young people in nursing homes and their families to be informed, make choices and tell their stories

Providing an evidence base

Conducting and fostering research that provides an evidence base for policy change

Building expertise

Fostering innovation and collaboration to improve the quality of services

Developing integrated supported housing

Increasing the range and number of supported accommodation options.

Work to Date

Over the past five years the Summer Foundation has had ten articles published in peer reviewed journals and produced five reports that provide an evidence base for policy change related this target group.

Key publications include the *From a home to their homes* DVD and booklet to enable people with disability and families make an informed choice about housing and support options and *Younger People in Residential Aged Care: Support needs, preferences and future directions*, which aggregates the data of 105 people under 50 living in aged care in Victoria.

The Summer Foundation has also been engaged by the Victorian Government Department of Human Services (DHS) Disability Services to undertake a Quality of Life Evaluation for individuals receiving support services through the *my future my choice* initiative. The final report is due January 2012.



Launched in 2009, Building Better Lives is a state-wide collaborative campaign led by the Summer Foundation that brings a range of disability organisations together under the one banner to resolve the issue of young people in nursing homes in Victoria. The campaign aims to raise awareness and secure funding from the public and corporate community in order to build Australia's first integrated housing model, where young people with disability will live in their own apartments peppered throughout a larger residential development with other members of the community. This is a critical step towards the social inclusion of people with disability.

Through the Building Better Lives ambassador program eight young people with a disability have been able to tell their story and engage in systemic advocacy. Theirs is a powerful voice that must be heard to reach the hearts and minds of our community. A billboard advertising campaign that began last year has been enhanced with the recent broadcast of the Building Better Lives cinema and radio commercials throughout Victoria, which are about to be further complemented with television advertising. Significant pro bono advertising creation and support has been acquired through the work of the Building Better Lives committee.

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