



Senate Inquiry into the adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia



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Average age of RAC residents is **84 YEARS**

**27%**

are parents of school age children



**45%**

seldom or never participate in leisure activities in the community

Over

**6000**

people **under 65** live in Residential Aged Care (RAC)

**605**

people under 50 live in RAC

Prior to their first admission to RAC 59% of young people are in hospital

**46%**

are in partnered relationships

**53%** of young people in aged care receive a visit from of friend **LESS THAN ONCE PER YEAR**



## About the Summer Foundation

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The Summer Foundation, established in 2006, is an organisation that works to change the human services policies and practices related to young people (18-64 years old) living in, or at risk of, entering residential aged care (RAC) facilities.

**OUR VISION** is that young people with disability and complex support needs will have inherent value as members of our society, with access to services and housing that supports their health and wellbeing.

**OUR MISSION** is to stop young people from being forced to live in nursing homes because there is nowhere else for them.



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### The Summer Foundation is working in three key ways to support change:

1. **Research:** conducting and fostering research that provides an evidence base for policy change;
  2. **Creating a movement:** supporting people with disability to tell their story, raise awareness and keep the issue on the political and public agenda; and
  3. **Housing:** developing integrated housing and support demonstration projects in order to increase the range and number of supported housing options.
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**Our submission to the Senate Inquiry draws on the insights arising from our work, current research, and collaboration with people with disability and their families and other organisations.**

## Glossary of Terms

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ABI	Acquired Brain Injury
ABI:STR	Acquired Brain Injury: Slow to Recover Program
ACAT	Aged Care Assessment Teams
AIHW	Australian Institute of Health and Welfare
COAG	Council of Australian Governments
CRPD	Convention on the Rights of Persons with Disabilities
CSTDA	Commonwealth State Territory Disability Agreement
DHS	Victorian Government Department of Human Services
HACC	Home and Community Care
HARP	Hospital Admission Risk Program
ISP	Individual Support Package
LAC	Local Area Coordinators (NDIS)
MATS	Mobile Assessment and Treatment Service
MS	Multiple Sclerosis
NDA	National Disability Agreement
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NRAS	National Rental Affordability Scheme
OH&S	Occupational Health and Safety
PEG	Percutaneous Endoscopic Gastrostomy
RAC	Residential Aged Care
SAIF	Shared Accommodation Innovation Fund
SWS	Sir William Street
TAC	Transport Accident Commission
UN's	United Nations
YPIRAC	Younger People in Residential Aged Care

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## Executive Summary

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There are too many young Australians stuck in residential aged care (RAC). This is a serious social issue, which can – and must – be fixed. Over 6000 people under the age of 65 live in RAC, 605 of whom are under 50 years of age <sup>1</sup>.

Young people with disability living in RAC are one of the most marginalised and isolated groups of people in our society. Fifty three per cent of young people in RAC receive a visit from a friend less than once per year and 82% seldom or never visit their friends. They generally lead impoverished lives, characterised by loneliness and boredom. They are effectively excluded from society with 45% seldom or never participating in leisure activities in the community <sup>2</sup>.

### **Impact of the Younger People In Residential Aged Care Initiative**

During the five year Younger People in Residential Aged Care (YPIRAC) program (2006-11), 250 people were assisted to move out of RAC and a further 244 people avoided being admitted to RAC. People who moved out of RAC went outside more often, had more opportunities to make everyday choices and spent fewer hours in bed <sup>3</sup>. However, many people missed out on funding through the YPIRAC program. Of the 715 people under 50 living in RAC in 2010-11 in Australia, an estimated (62%) people under 50 remained in RAC and did not receive additional disability supports from YPIRAC <sup>4</sup>.

There has been an overall downward trend in the number of people under 50 admitted to RAC from 1999-2000 through to 2012-13. However, it is noteworthy that a large increase occurred from 180 new admissions in 2011-12 to 292 new admissions in 2012-13. Overall, the number of people aged 50-59 admitted to RAC shows an increasing trend with a noteworthy increase from 761 new admissions in 2011-12 to 1050 new admissions in 2012-13. These figures demonstrate the YPIRAC initiative made a significant difference to the lives of the people who received services but did not create the systemic change needed to stem the flow of young people into RAC<sup>1 4</sup>.

## **What difference will the NDIS make?**

People under 65 years of age living in RAC are eligible for funding through the NDIS. The NDIS is one part of the solution to the issue of young people being placed in RAC. The NDIS will provide the crucial funding for support that young people in RAC, or at risk of entry, need to live in the community. However, the NDIS cannot on its own stop the inappropriate placement of young people in RAC<sup>3</sup>. More accessible and affordable housing needs to be built. We also need to change the system to prevent new admissions.

## **Key issues and potential solutions**

There are five key areas that must be addressed to resolve the issue of young people in RAC in Australia.

### **1. Ensure that young people in RAC get access to the NDIS**

Based on current research and experience with previous government programs, most young people in RAC will miss out on services funded through the NDIS unless someone goes to each RAC facility to find, engage and support them to register with the NDIA. Initial research in the NDIS trial sites has found that 58% of young people in RAC are not registered with the NDIA in the trial sites. More than 18% of young people in RAC do not have anyone to advocate for them.

The Summer Foundation's action research in the NDIS trial sites highlights the importance of collaboration between the NDIA and other organisations to streamline the registration process for young people in RAC with an obvious disability. There is also scope for NDIA to use Commonwealth data to find and inform younger people in RAC and obtain information that assists in the registration and planning process. In the short term, all 321 people under 65 in RAC in the trial sites need to be informed and supported to access the NDIS. In preparation for the national rollout of the NDIS, a strategy to increase the scale of this 'case finding' work from July 2016 to reach the 6000 people under 65 living in RAC who will be eligible for funding for services and equipment is essential.

## **2. Build the capacity of young people in RAC**

Most (56%) people under 65 living in RAC in the trial sites are not receiving any disability support services.

Capacity to engage in goal setting and planning is often hampered by limited knowledge of the possibilities for life beyond RAC. Resources that build the capacity of young people in RAC and their families to be actively involved in setting goals, developing their plan and choosing services are needed.

## **3. Prevent new admissions**

Once in RAC, young people lose skills and their social networks diminish. Preventing new admissions is a much more efficient use of resources than letting young people be admitted to RAC and then moving them out. Most (59%) young people are admitted to an acute or rehabilitation hospital before their first admission to RAC. Preventing new admissions requires investment and involvement from both the health and disability sectors. Hospital liaison workers funded by the NDIA would facilitate discharge planning by exploring discharge options and coordinating supports, home modifications and equipment as early as possible in the hospital stay.

Slow stream rehabilitation and transitional services are needed in every state and territory to give people with severe brain injuries in acute hospitals the time they need to demonstrate their potential before they are forced into RAC. Proactive case co-ordination is also required to respond to the changing needs of people with degenerative disorders (e.g. multiple sclerosis, Huntington's disease and motor neuron disease) living in the community.

Young people in RAC are often highly susceptible to secondary conditions that can make them critically ill or result in premature death. These secondary medical conditions include pressure areas (31%), contractures (31%), urinary tract infections (23%) and chest infections or pneumonia (18%). Periodic admissions to acute health services are common – 42% of young people in RAC are admitted to an acute hospital each year, with some people experiencing multiple admissions. When people with disability with high and complex care needs are admitted to acute hospitals they often require 1:1 support from disability support workers.

Health outreach services that combine direct care with a 24-hour on-call service are needed for people in the target group who require intermittent nursing care. A pilot program jointly supported by Health and NDIA based on the [Alfred Mobile Assessment and Treatment Service \(MATS\)](#) program would provide an evidence base for a model of community based health support for people with disability with high and complex needs to be rolled out across Australia. This pilot is likely to demonstrate cost efficiencies for both Health and the NDIA.

#### **4. Increase the range and scale of housing**

The NDIS has limited funding for capital to support the development of new housing for young people in RAC. Due to the current shortage of accessible and affordable housing we do not expect many young people to move out of aged care facilities as a result of the NDIS. We need a range of options including models that enable people to live with their partner and/or children. Many (46%) young people in RAC are in partner relationships and 27% are parents of school aged children <sup>2</sup>. Australia desperately needs a long term strategy to create more housing that is both accessible and affordable. Rather than continuing to build segregated specialist housing, the housing needs of people with disability need to be incorporated into mainstream housing strategy.

There are a number of housing demonstration projects that have either recently been developed or are about to commence that integrate housing for people with high and complex care needs into mainstream housing. These housing projects aim to show how well located and designed housing that incorporates technology and quality support, can increase independence, reduce reliance on paid supports and reduce lifetime care costs. Research, stories and evaluations that translate the knowledge generated from these projects will enable others to replicate these models. We need collaborative strategies to influence key decision makers in government, planning, community housing organisations and developers to ensure that housing for people with disability is incorporated into mainstream housing policy and projects.

## **5. Cross-sector Collaboration**

Solving the issue of young people in RAC on a sustainable basis requires strong government policy leadership and effective collaboration strategies across many sectors. No one sector has the expertise or resources to prevent new admissions of young people to RAC or to develop the range and scale of housing, rehabilitation and ongoing support required for this target group. The complex needs of young people in RAC requires a more co-ordinated approach that involves health, housing and aged care rather than just looking to disability services to solve the issue alone as has happened in the past.



Young people in nursing homes are effectively excluded from society and experience deep and persistent disadvantage. Research by the Summer Foundation and Monash University found that 53% of young people in RAC were visited by friends less than once a year. One-third never have the opportunity to go shopping, visit friends and family or enjoy other leisure activities.

RAC facilities are not designed or resourced to support young people with high clinical needs to participate in everyday activities or the life of their community<sup>5-8</sup>. Rather, RAC facilities are designed to provide accommodation, personal and nursing care to frail older people at the end stage of their life. The average age of residents in aged care facilities is 84 years<sup>1</sup>. Most people who enter RAC on a permanent basis die within a couple of years with the average length of stay being 28 months<sup>1</sup>.

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**The Summer Foundation has worked with people who were admitted to aged care in their teens or early twenties and remained there for more than twenty years.**

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The issue of young people in RAC is so complex because it involves legislation, regulation, policy, funding and practices across the aged care, disability, health and housing sectors. A lack of effective co-ordination in strategic policy and program development and the split of responsibilities between the state and territory and federal governments compounds the problem.

Historically there has been little incentive for the state/territory governments to move young people out of RAC or prevent new admissions. RAC beds are funded by the federal government and when a young person moves out, the substantial recurrent cost of supporting them in the community shifts to state-based disability services, all of which already have huge unmet demand for housing and support<sup>11</sup>. Therefore, any substantial progress towards developing appropriate alternative housing and support options for young

people in RAC requires collaboration and joint funding from the state/territory governments and the federal government.

In July 2008, the Australian Government ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD). Article 19 of the United Nations CRPD 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” 9, 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” 9, p. 14. There is a disconnection between the policy aspirations outlined in the UN’s CRPD and the lived experience of people with disabilities in Australia 10. In reality, in 2015 people with disability 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.

In 1995, the Western Australian Government launched their Young People in Nursing Homes project <sup>12-14</sup>. The project was achieved through the Commonwealth State Territory Disability Agreement (CSTDA) and resulted in the closure of 95 nursing home beds and the transfer of funding for the target group to community-based disability support providers. Capital funding was made available through Homewest and the Health Department to provide buildings and therapeutic equipment. Over a four-year period, this project developed a range of alternative housing and support options for 95 young people previously living in RAC <sup>12</sup>. However, over time, the vacancies in RAC created by this project were back-filled by a new cohort of young people requiring nursing home level of care <sup>15</sup>. One of the key learnings from this project was the need for sustained investment in alternative housing and support options and systemic change to prevent new admissions of young people to RAC.

In June 2004, the Australian Government announced a Senate Inquiry into Aged Care <sup>16</sup>. The inclusion of young people in RAC in the Inquiry’s terms of reference was a significant step in the federal government committing to understand the needs of young people in RAC. This inquiry examined “*the appropriateness of young people with disabilities being*

*accommodated in RAC facilities and the extent to which residents with special needs, such as dementia, mental illness or specific conditions are met under current funding arrangements*" <sup>16, p.1</sup>. Public hearings were conducted between August 2004 and April 2005 with 243 submissions made between July 2004 and June 2005 <sup>17</sup>. The report from this inquiry, released in June 2005, along with the transcripts and submissions, provided a rich array of anecdotal evidence about the social exclusion of young people in RAC. The report concluded that it was unacceptable in most circumstances for young people with disability to be housed in RAC <sup>16</sup>. In response to the concerns raised in the 2005 Senate Inquiry report, a new national initiative was agreed upon by COAG in February 2006.

Governments jointly established and funded a national five-year program called the Younger People in Residential Aged Care (YPIRAC) initiative, providing \$244 million, and with an initial priority target being people aged under 50. Prior to this program, in June 2006, there were 1007 people under 50 years living in RAC in Australia <sup>15</sup>. This national program aimed to reduce the total number of young people in RAC by up to 689 people by July 2011 <sup>18</sup>.

The YPIRAC initiative, which concluded in 2011, made a significant difference to the lives of those people who received funding through it. For the duration of the program, the service system was responsive in identifying, assessing needs and providing support to this target group. During the five-year program an estimated 250 Australians were assisted to move out and a further 244 people avoided being admitted to aged care <sup>19</sup>. Sixty-five new shared supported accommodation services for more than 350 young people in RAC or at risk of admission were established throughout Australia. The people in this initiative reported marked improvements in their quality of life, as well as increased opportunities to make everyday choices and participate in valued activities <sup>3, 20, 21</sup>.

The YPIRAC initiative involved collaboration between the state, territory and federal governments and was a substantial first step in a collaborative approach to addressing the issue of young people in RAC in Australia. The program was implemented through disability services departments within each state and territory government. However, there was limited collaboration with housing and health departments <sup>3, 21-23</sup>. Although this initiative had a time limited impact, it did not create the systemic change required to have a long-term impact on the issue of young people in RAC. Once the initiative ended, the system largely reverted to the way things were in the past.

The new shared supported accommodation services for this target group are full and vacancies are usually only created when a resident dies. In Victoria, there is also increased pressure from state government disability services to utilise any new vacancies in these houses for their highest priority clients, even though they may not be in the YPIRAC target group. Younger people are again being placed in RAC facilities, and nearly 300 people under 50 are once again at risk of admission to aged care each year in Australia <sup>1</sup>.

The National Disability Insurance Scheme (NDIS) has the potential to make a significant difference to the lives of young people in RAC in Australia. The Productivity Commission specifically identified this target group in their final report <sup>24</sup>. The NDIS will provide funding for the support and equipment that young people in RAC or at risk of admission to RAC desperately need.

**The aims of this submission are to:**

1. Summarise the characteristics, housing and support needs and preferences of young people in RAC in Australia.
2. Examine the outcomes and impact of services provided to young people in RAC or at risk of admission to RAC.
3. Provide an evidence base to identify potential solutions and the next steps to resolving the issue of young people in RAC in Australia.



## 2. Characteristics & Support Needs

Improved medical technology and rehabilitation have increased the survival rates and life expectancy of people with severe acquired brain injury (ABI) and complex care needs <sup>25-27</sup>. People who sustain very severe brain injuries, who once would have died at the scene of the accident or in hospital, are now surviving. People with disability in general, and people with degenerative neurological conditions are also living longer <sup>28-30</sup>. Advances in medical technology have led to a new group of people with catastrophic impairments and complex support needs who challenge a service system which is ill-equipped to cope with their needs. This group experiences deep and persistent disadvantage related to finance, housing, social inclusion and access to services.

### **Disability**

Most young people in aged care have a brain injury (58%) while others have late onset degenerative neurological disabilities such as multiple sclerosis (14%) and Huntington's disease (9%). Some (13%) have more than one type of disability <sup>2</sup>.

Disability services in Australia have largely been developed with a focus on the needs of people with congenital disabilities, and their services are underpinned by a “developmental framework” <sup>31</sup>. This developmental framework has been valuable in ensuring that there isn't an over-medicalisation of services, and focuses on facilitating the transition of people through age-related stages from infancy to adulthood. The specific support provided to people with an intellectual disability and people with ABI may superficially appear to be the same but in fact fundamentally different approaches are required <sup>31</sup>.

People with ABI and other acquired disabilities require services that are underpinned by a “rehabilitation framework” - one that supports them to re-gain, to the highest extent possible, skills and life-roles lost as a consequence of their injury or onset of their condition. It involves planning for the recovery of individual abilities and capacity for community participation, considers pre-injury roles and taps into remaining skills, strengths and abilities.

Ideally, the rehabilitative framework involves collaboration between acute and post-acute allied health and medical services, and disability supports. Rehabilitation is embedded in the disability response, it does not simply involve referral back and forth with the health system at specific times for particular interventions. In that sense, the current division of responsibility between health and the NDIS overlooks the benefits that flow from a more advanced policy-approach integrating health and disability. This approach also supports people to create a new identity for themselves if they are unable to return to previous roles such as the 'breadwinner' of the family, or return to professional work <sup>32</sup>.

## **Health**

In addition to their primary disability, many people have sensory impairments (64%), symptoms of mental health issues (71%) and secondary health conditions. The most common mental health issue experienced by young people in RAC is depression (50%) <sup>2</sup>.

Most young people with very high care needs living in RAC have, potentially, many years of life ahead of them. However, many people in this population have been described as having a 'narrow margin of health' <sup>33</sup>. This means that they are highly susceptible to secondary conditions that can make them critically ill or result in premature death. These secondary medical conditions include pressure areas (31%), contractures (31%), urinary tract infections (23%) and chest infections or pneumonia (18%). Most people have a complex combination of health needs, 88% have three or more health problems <sup>2</sup>.

Periodic admissions to acute health services are common. Forty two percent of young people in RAC are admitted to an acute hospital each year, with some people experiencing multiple admissions. Approximately 16% have an elective admission each year related to a range of health problems including orthopaedic issues (4%), Percutaneous endoscopic gastrostomy (PEG) related issues (3%), catheter insertions (2%) and gynaecological problems (2%). Approximately 30% have a non-elective admission to an acute hospital each year resulting from health issues such as PEG management (4%), chest infections or pneumonia (4%), seizures (3%) and psychiatric issues (3%) <sup>2</sup>.

There is a common misconception that young people with complex care needs are ‘safer’ in RAC 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 RAC died, with an average of 21.4 deaths per year <sup>34</sup>.

During that 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 with degenerative conditions and cancer likely to account for some of these deaths. However research shows that less than 28% of people under 60 years in RAC have a degenerative condition such as Huntington’s disease and only 1% have a diagnosis of cancer <sup>35</sup>. Given the relatively small incidence, these conditions alone do not account for the high rate of death. Looking at the number of falls, hospital admissions and the high death rate, it appears that RAC does not offer the type of support required to manage the health care needs of young people with disability.

A study <sup>36</sup> into the deaths of people under 50 in RAC in Victoria found that while there was an average of 21 deaths per year in a population of 210, most deaths are not reported to the Coroner’s Office. The study concluded that monitoring and cross-sectoral work is required to better understand the needs of this population and develop solutions to meet their complex needs.

Many of the episodes of illness and hospital admissions experienced by young people in RAC appear to be predictable and preventable <sup>2</sup>. The skills, experience and training of the aged care workforce overall do not appear to match the requirements for this group of residents.

## **Cognition and communication**

Contrary to the assumption that young people in aged care are not conscious of their environment, research indicates that many people (60%) are fully aware of their environment and oriented to time, place and person. Approximately 30% are partially aware – they are conscious and awake but may have memory difficulties or experience significant levels of confusion. Only 9% are in a minimally conscious state. Many (48%) have difficulty communicating their basic needs and approximately 7% are prone to wandering or getting lost <sup>2</sup>.

## **Mobility**

Some (47%) people need assistance with mobility inside the RAC facility and 40% require assistance with moving in bed, e.g. turning. Most (67%) require assistance to get in and out of the place they live and 71% require assistance to get around their local community. A large proportion of the people require specialised equipment such as customised wheelchairs and accessories, walking frames, slide sheets, hoists, cushions, commodes, beds, mattresses, overlays, recliner lounge chairs, over-bed tables, portable ramps, slings, communication devices, computers and adaptive switches <sup>2</sup>. The funding model in aged care does not provide sufficiently for these specialised aids and equipment.

## **Challenging behaviour**

Most people (78%) display at least one challenging behaviour of varying severity. Challenging behaviour is behaviour causing distress to the person with the disability or is disruptive to other people causing them distress or making them feel uncomfortable. Many young people with disability have complex combinations of challenging behaviours with 39% having three or more challenging behaviours. Lack of initiation and verbal aggression are the most common behaviours identified <sup>2</sup>.

## **Support needs**

The support needs of young people in RAC are varied. 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 <sup>2</sup>. Young people in RAC are a diverse group with a complex range of health and support needs that are not adequately met within the RAC environment <sup>2</sup>. Most young people in RAC require a rehabilitative approach to their support, allowing them to recover capacities that may have been lost, but this approach is contrary to the largely palliative approach required for most RAC residents at the end stage of their lives.

## **Social circumstances**

Many (46%) of young people in RAC are in partner relationships and 27% are parents of school aged children <sup>2</sup> Most (93%) of young people with disability living in RAC are in receipt of a Disability Support Pension <sup>2</sup>. Generally 85% of their Disability Support Pension is used to pay RAC Daily Bed Fee, which means that young people in RAC have very limited disposable income. This group experiences deep and persistent disadvantage related to finance, housing, social inclusion and access to services.

## **Social inclusion**

Young people in RAC experience high levels of social isolation from peers (53% receive a visit from a friend less than once a year or never) and limited community access (21% seldom or never go outside). Moreover, many people are effectively excluded from life in the community (34% almost never participate in community-based activities such as shopping or other leisure activities) <sup>2</sup>.

## **Impact of RAC placement on families**

Past research has not only illustrated the negative impact RAC placement has on young people with disability, but also the family distress experienced when a young person is placed in RAC. In qualitative interviews, many family members of YPIRAC reported high levels of distress when they walked through the doors of an aged care facility to visit their family member. Families reported feeling obliged to spend long hours in the RAC to provide their family member with company and check they were receiving adequate care. They expressed their dismay that RAC services lacked age appropriate, meaningful activities for younger residents, which meant many of the participants would spend all day in their bed or room alone, without opportunities for socialisation or participation. Families described their frustrations regarding the institutionalised elements of RAC, such as rigid routines, lack of choice and individual support, as well as recreational programs that only catered for the elderly (Winkler, Holgate, Sloan & Callaway, 2012). This research demonstrates that placement of a young person with disability in RAC not only impacts the individual, but also has implications for the wellbeing of the family. There is a broader social and economic caregiver burden that may be experienced by families when a young person is placed in RAC.

*I hate it. I hate it. I hate coming here (to RAC). But Tom's here... people come here to die... it's geared towards dying well... not geared towards living well. But Tom's still got his whole life in front of him."*  
*Tom's mother.*

*"I think they forgot that Ned is a young man... he doesn't need to be in bed all day...he's not elderly and he's not sick." Ned's mother.*

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**Young people in RAC have many of the same needs and life goals as anyone else. They want somewhere to live, someone to love and something to do. Innovative alternatives to young people with disability living in aged care are crucial for them to enjoy the kind of life that the rest of us take for granted.**

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#### **Implications for Potential Solutions**

- Young people in RAC are a diverse group with a range of disabilities and support needs
- Young people in RAC often have a range of secondary health conditions
- They need more than just disability supports, they need proactive health care in the community to prevent admissions to RAC and minimise hospitalisations.
- Most young people in RAC acquire a disability as an adult – they are often in partner relationships (48%) and some (27%) have school age children.
- We need a range of housing and support options including models that enable people to live with their partner and/or children.
- Most (96%) young people in RAC are on a disability support pension. Their financial disadvantage also limits their housing options.

### 3. How many young people are in RAC?

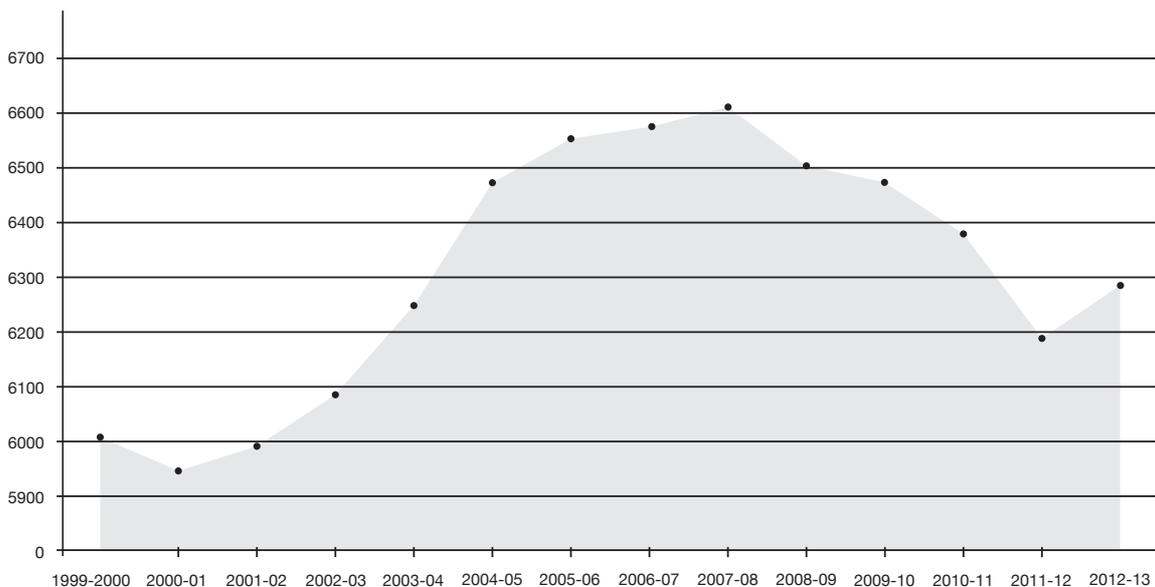
This chapter examines the trends in the number of young people in RAC in this century. The trend analysis examines two key indicators related to the number of young people in RAC: the number of permanent residents and the number of new admissions. Australia wide data collected by the AIHW in the financial years from 1999-2000 to 2012-2013 were used for these analyses<sup>1,37</sup>. Statistically significant overall time based trends and significant single year changes from overall previous levels are reported for the under 65 year old age group and subgroups within this larger group.

#### Number of Permanent Residents and New Admissions under 65 years

##### Permanent Residents

Overall results are consistent with a significant increasing trend ( $p < .001$ ) in the number of permanent residents from 1999-2013 (Figure 3.1). Comparison of single year levels with previous levels showed the number of permanent residents increased significantly ( $p < .05$ ) from 2004 to 2009.

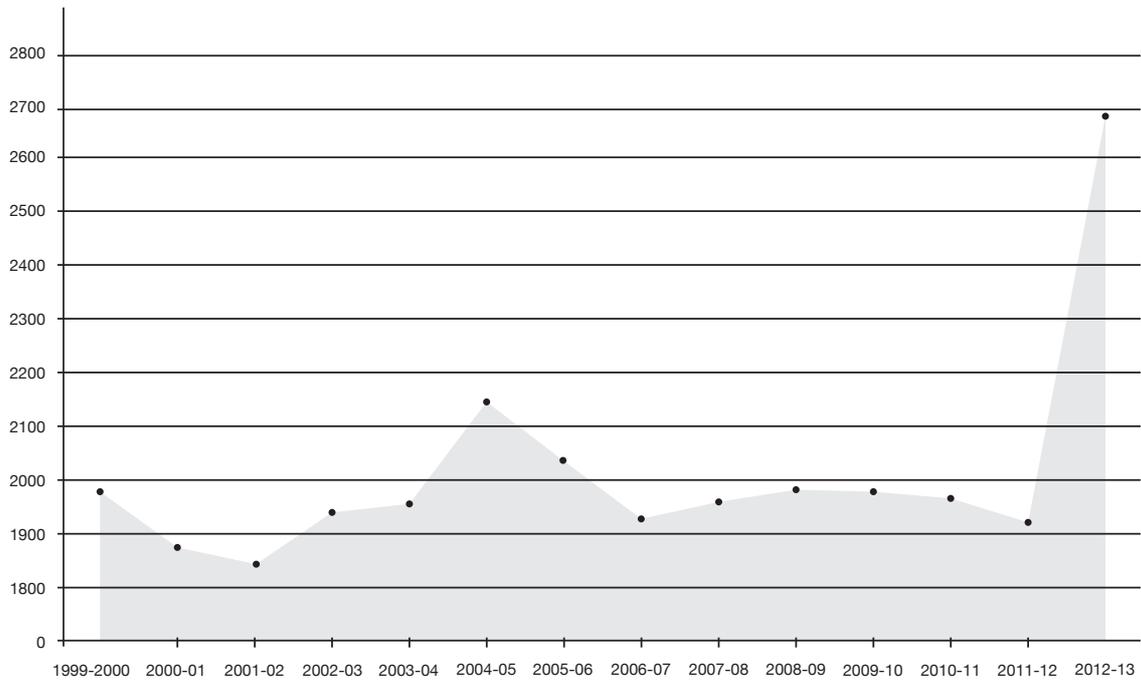
Figure 3.1 Number of people under 65 years living in RAC 1999-2013



### Admissions

Overall, there is a significant increasing trend ( $p < .01$ ) in the number of new admissions from 1999-2013 (Figure 3.2). This overall trend is primarily due to the large and significant peak in 2012-13 and the smaller significant increase in 2004-05.

**Figure 3.2 Number of people under 65 admitted to RAC 1999-2013**

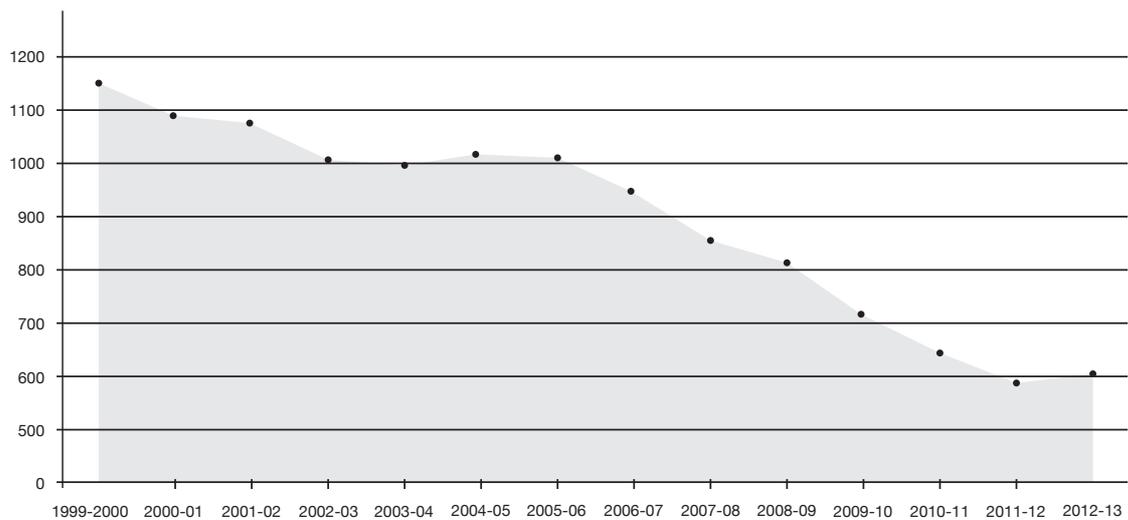


## Number of Permanent Residents by Age Sub-Group

### Under 50 years

The number of permanent residents under 50 overall shows a significant decreasing trend ( $p < .001$ ) from 1999-2012 (Figure 3.3) with significant single year reductions evident from 2006-07 through to 2012-13.

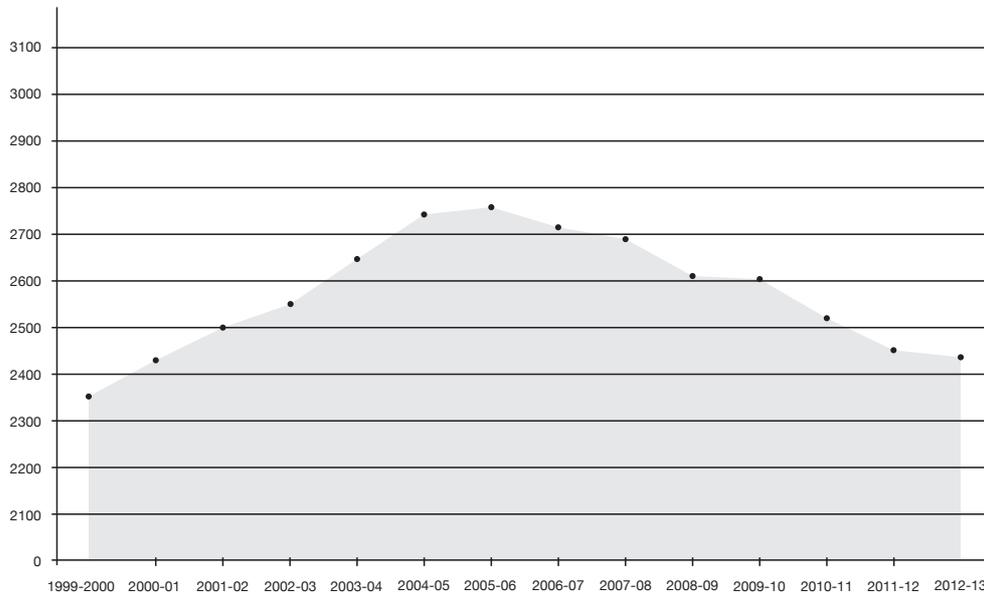
Figure 3.3 Number of people under 50 living in RAC 1999-2013



### 50-59 years

The trend in this age group increases significantly overall and is characterised by significant single year increases from 2002-03 through to 2006-07 (Figure 3.4).

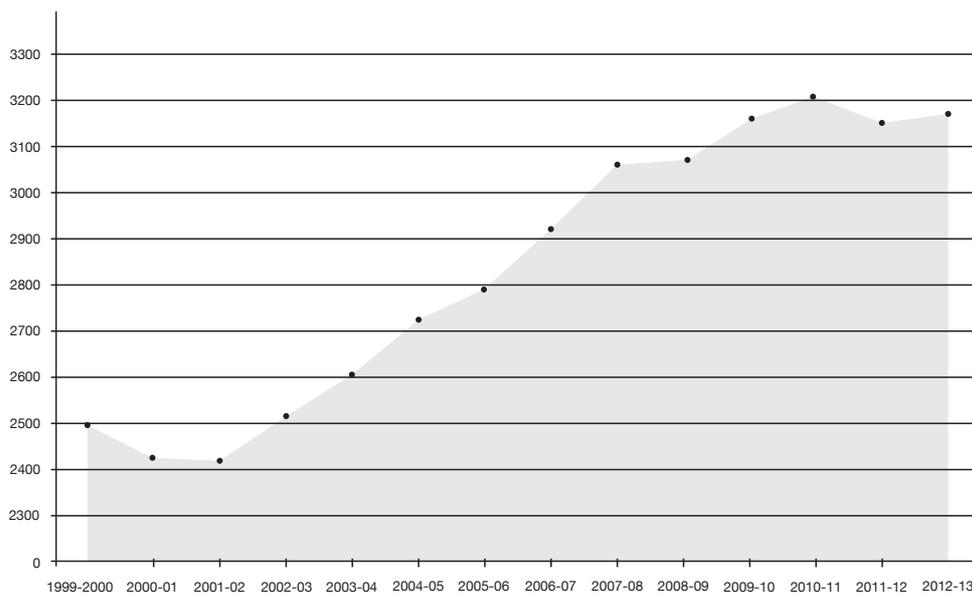
**Figure 3.4 Number of people aged 50-59 year living in RAC 1999-2013**



### 60-64 years

The overall data in this age group shows a significant increasing trend ( $p < .001$ ) with significant single year growth evident from 2004-05 through to 2012-13 (Figure 3.5).

**Figure 3.5 Number of people aged 60-65 year living in RAC 1999-2013**

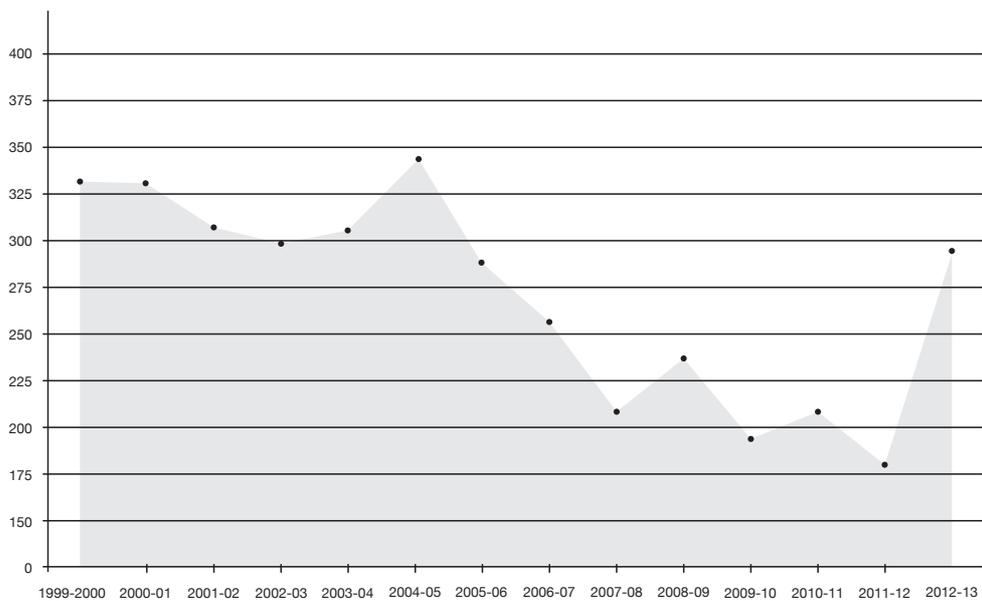


## Number of new Admissions by Age Sub-Group

### Under 50 years

The number of new admissions under 50 overall shows a significant decreasing trend from 1999-2012 (Figure 3.6) with significant single year reductions evident in 2006-07 and 2010-11.

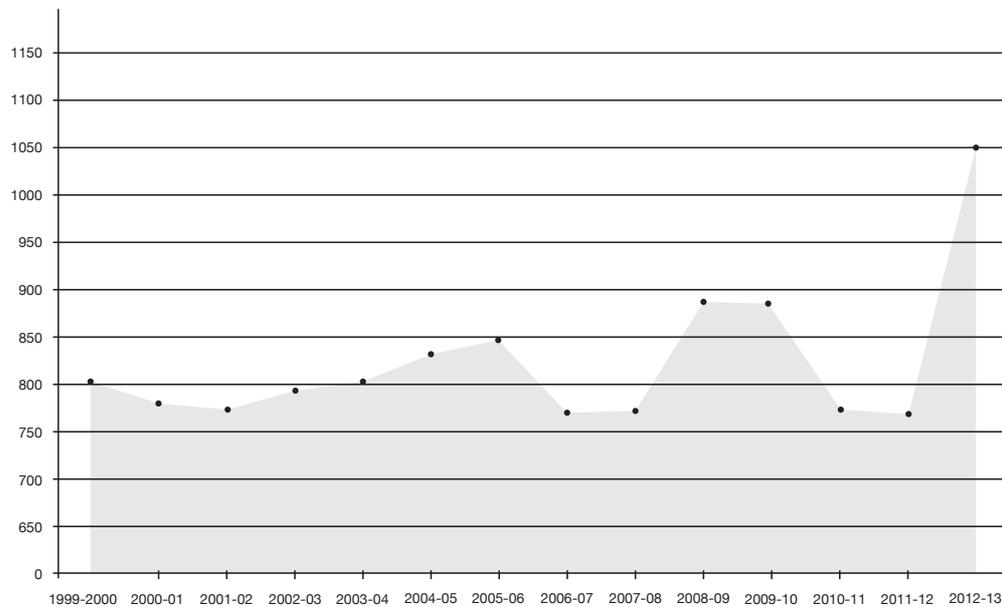
**Figure 3.6 Number of people under 50 years admitted to RAC 1999-2013**



### 50-59 years

The overall trend in this age group is a significant increasing trend, which is primarily due to the large, and significant peak in 2012-13 and the smaller peak non-significant increase in 2005-06 (Figure 3.7).

**Figure 3.7 Number of people aged 50-59 years admitted to RAC 1999-2013**

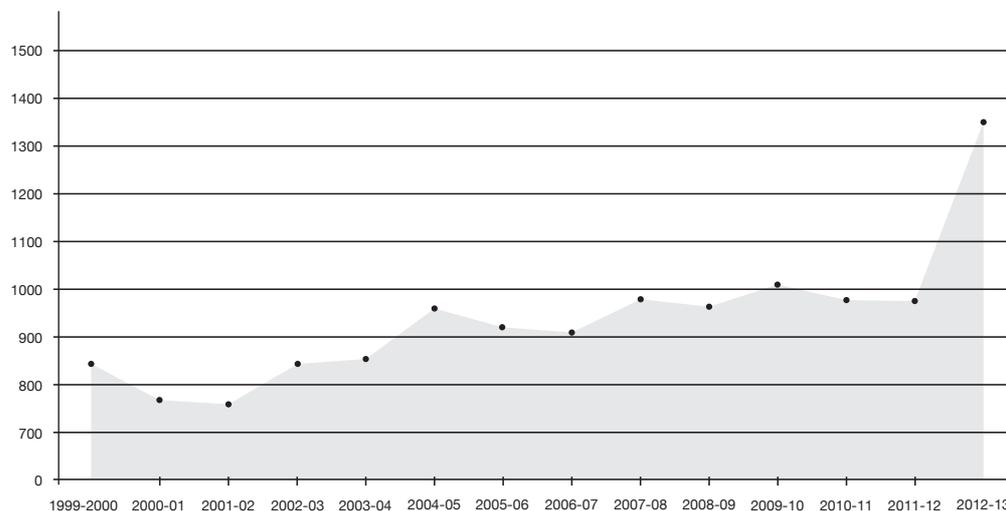


There has been an increasing number of people aged 50-59 admitted each year to RAC since 1999. The YPIRAC initiative targeted people under 50 and thus did not make an impact on this age group.

## 60-64 years

The overall data in this age group shows a statistically significant increasing trend ( $p < .001$ ) with significant single year growth evident from 2004-05 through to 2012-13 (Figure 3.8).

**Figure 3.8 Number of people aged 60-65 years admitted to RAC 1999-2013**



There has been an overall downward trend in the number of people under 50 admitted to RAC from 1999-2000 through to 2012-13. However, it is noteworthy that a relatively large increase occurred from 180 new admissions in 2011-12 to 292 new admissions in 2012-13. Overall, the number of people aged 50-59 admitted to RAC shows an increasing trend with a noteworthy change from 761 new admissions in 2011-12 to 1050 new admissions in 2012-13. The YPIRAC initiative made a significant difference to the lives of the people who received services but did not create the systemic change needed required to stem the flow of young people into RAC.

### **Implications for Potential Solutions**

- The overall trend this century has been a decrease in the number of people under 50 admitted to RAC.
- There was an increase in the number of people under 50 admitted to RAC in 2012-13.
- Nearly 300 people under 50 continue to be admitted to RAC each year in Australia.
- The YPIRAC initiative did not create the systemic change required to stem the flow of young people into RAC.



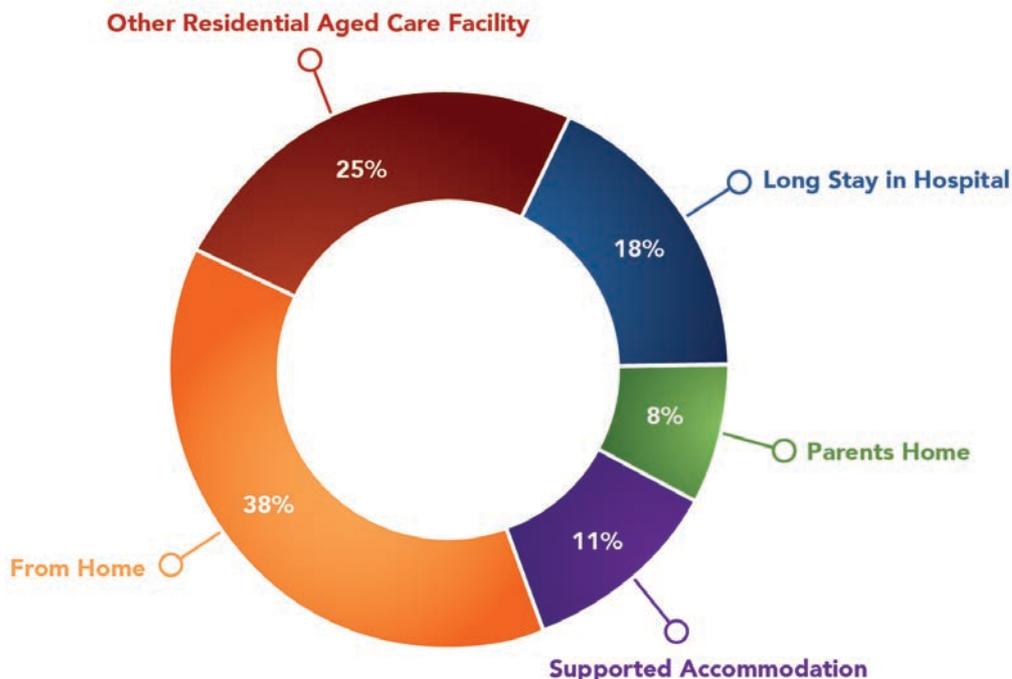
## 4. Why do young people end up in RAC?

Young people in RAC are a diverse group of people with a range of disabilities, health issues and social circumstances. There are a range of pathways into RAC, many people enter via the health care system while others enter straight from living in the community either from their own home or a group home.

### Residence prior to admission

Prior to their admission to an aged care facility many young people are living in their own home (38%) or their parent's home (8%) (Figure 4.1). Some (18%) have been in hospital for more than six months and a significant number (25%) come from another RAC facility. Many (35%) young people have lived in more than one RAC facility with 26% residing in 3-8 different RAC facilities.

Figure 4.1 Residence of young people in RAC prior to admission



Winkler, Sloan & Callaway Report 2007

## Pathways into RAC

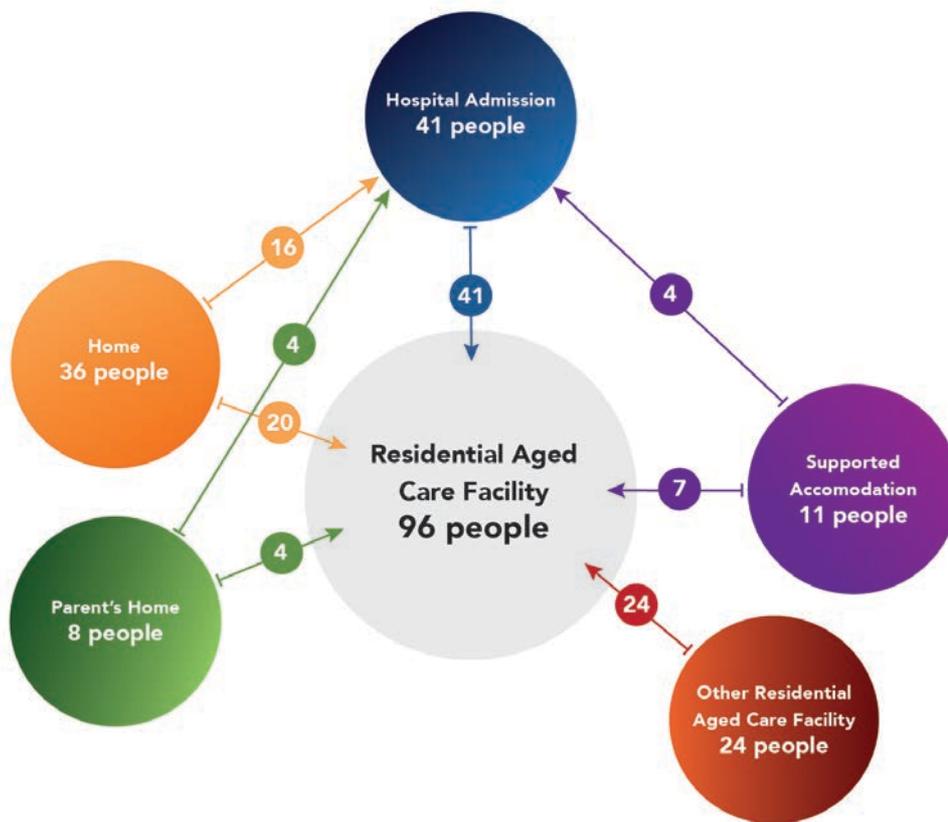
One of the main pathways of younger people into aged care is via an acute or rehabilitation hospital admission. The health system and disability services work on very different timelines. Hospitals are under increasing pressure to discharge patients as early as possible once they are medically stable, with health professionals forced to make early predictions on the patient's long term prognosis, or the patient's capacity to benefit from rehabilitation. This can result in some young people being admitted to RAC before they have had the time they need to demonstrate their potential for recovery.

Some families report that they were shocked at how quickly a decision was made to discharge their family member to RAC.

*“At the point when Michael's tracheotomy was removed the hospital staff abruptly shifted focus. The care and support was gone, our son was medically stable and we were directed to the basement of the hospital to find the discharge planner. We hadn't thought ahead to where Michael would go, our focus was on whether he would live or not when the trachy was removed...we didn't want him in a nursing home, we didn't want him to leave hospital, we just wanted him to recover”. Anne, Mother of Michael who was 25 years old when he sustained an acquired brain injury.*

Young people are admitted to RAC via a range of pathways (Figure 4.2). Prior to entering their current RAC facility, 43% of young people are in hospital. However some of these people are coming from other RAC facilities. Prior to their first RAC placement, 59% of young people have an interim hospital admission<sup>2</sup>. This suggests that disability services need to partner with health services to develop pathways from hospitals to community living in order to prevent new admissions.

Figure 4.2 Range of pathways to current RAC facility



Winkler, Sloan & Callaway Report 2007

### Factors that lead to RAC admissions

There are a range of factors that lead to the admission of young people to RAC. Most (58%) experience an increase in their support needs as a result of a degenerative condition, illness or injury prior to their first admission to RAC <sup>2</sup>.

Health complications led to Vicki's hospital admission, she recalls the conversation about her hospital discharge vividly;

*"The unit manager came to the end of my bed and bluntly and coldly told me I was going to a nursing home. I was devastated. I could not believe that was what it had got to in my life. I didn't know that a nursing home took young people."*

Some (16%) people living in a shared supported accommodation services are told that the service is no longer able to accommodate them. Others (16%) have a change in their social circumstance, where someone who previously supported them is no longer able to provide support <sup>2</sup>.

*Daniel has cerebral palsy and lived with his wife of 28 years, prior to being admitted to hospital to investigate deterioration in his abilities. He was discharged to in-patient rehabilitation. His stay was prolonged as his marriage broke down and no affordable accessible housing could be found. After nine months, Daniel aged 48, was discharged to RAC.*

*At the age of 42, Denis experienced a stroke. The family's dynamics changed abruptly and dramatically with Denis relying on his wife and young children for support. The family unit buckled under the pressure and Denis entered a RAC facility. After eighteen months, he moved out into a unit and secured a part time job. For the next three years Denis managed with the help of support workers. When an injured support worker was not replaced, Denis' independence began to unravel. Although he tried to manage with reduced support he could not, and was forced to return to the RAC facility. He remains there today.*

A small number of people (3%) are admitted to RAC largely due to lack of equipment, and others (6%) are admitted because they are not able to get the support they needed to remain in their own home <sup>2</sup>. Of the people living in the community with a disability prior to their admission to RAC, 33% said that increased support and resources would have enabled them to stay at home longer <sup>2</sup>.

*Helen lived with her husband and son when she was diagnosed with multiple sclerosis (MS). When she fell and broke her leg she was admitted to hospital. The discharge team assessed that she needed 27 hours of assistance per week to manage at home, and applied for an individual support package (ISP). There was no funding available to meet Helen's needs and she was discharged to RAC.*

Some young people in RAC report that they were initially told that the move to RAC was an interim decision but once admitted found themselves stuck there permanently.

*Chris, a man in his early 50s suffered a hypoxic brain injury. He was discharged from a major acute hospital to an in-patient rehabilitation unit. Being surrounded by others with far greater needs, the highly regimented environment didn't suit Chris and he accepted the offer of a 'transitional' bed in a RAC facility, on the premise that it would only be for four months. Having left rehabilitation early while he was still making gains, Chris was dismayed when after four months he was made a permanent resident of the RAC facility.*

*Prior to living in the current RAC, Hayden lived with his parents for 11 years. Hayden relied on his mother to meet all of his support needs. However his mother, due to ageing and health issues, was unable to continue to support him and, as a result he was initially placed in RAC for respite. At that time the general practitioner advised the family that given the mother's ailing health, Hayden should not return to the family home.*

Some young people at risk of admission to RAC are denied the rehabilitation they need because they do not have stable housing to return to.

*Lisa is a 30-year-old with an acquired brain injury who has been a patient in an acute hospital for eight months. She goes about her daily activities relatively independently, using an electric wheelchair to get around but needs slow stream rehabilitation to return to living in the community. Prior to her injury she was in crisis accommodation. Slow stream rehabilitation services have refused to admit her because she does not have a discharge destination. At this stage her only option is RAC.*

## Young people at risk of admission to RAC

There is limited information available on the number of young people in Australia at risk of admission to aged care. One possible data source is information from Aged Care Assessment Teams (ACATs). ACATs are responsible for assessing older people, making recommendations for their long-term care and support and approvals for Australian Government-subsidised aged care services<sup>19</sup>. ACATs provide information on suitable housing and support options, and can help arrange access or referral to appropriate residential or community support services such as Home and Community Care (HACC). An ACAT assessment and approval is required before people (including younger people) can access RAC.

Generally, people need to be over 65 years to be eligible for RAC services in Australia. Under the Aged Care Act, people younger than 65 with disability are able to enter RAC 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<sup>38</sup>.

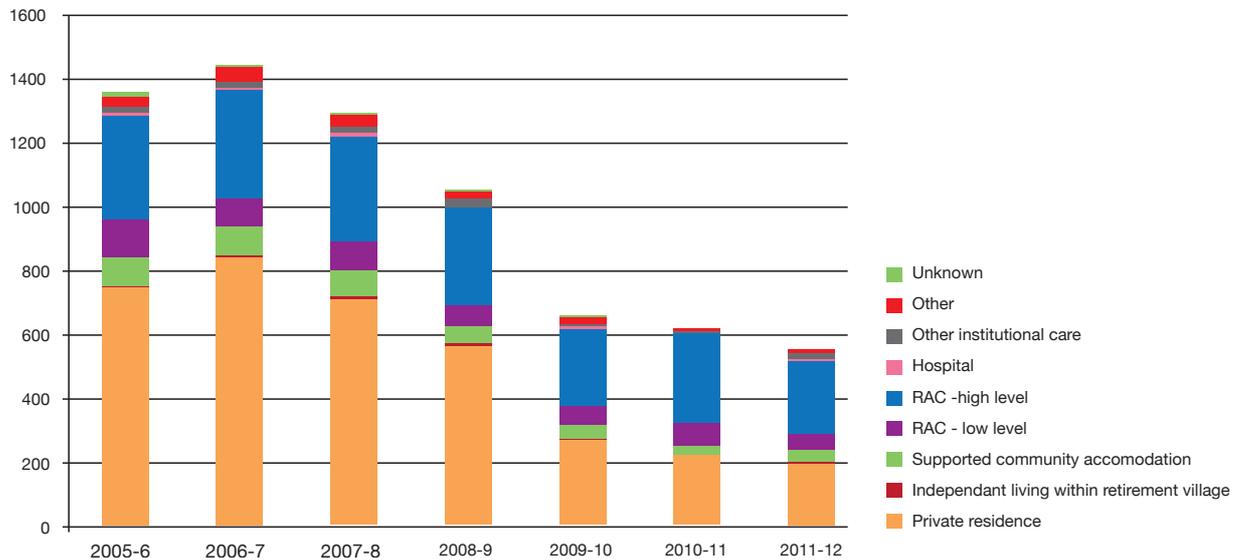
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**Young people are not necessarily placed in RAC because they require 24-hour nursing care (although they may require 24-hour supervision and assistance); it is usually because there are no practical or viable alternatives.**

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In analysing the national completed ACAT assessment data from 2005-06 to 2011-12 there have been some significant trends. The overall data in the under 50 years age groups show a statistically significant decreasing trend ( $p < .05$ ). In 2005-6, 1360 people under 50 had completed ACAT assessments, by 2011-12 this number had reduced to 556 people. Figure 4.3 shows the recommended long-term care setting of completed ACAT assessments for people aged under 50.

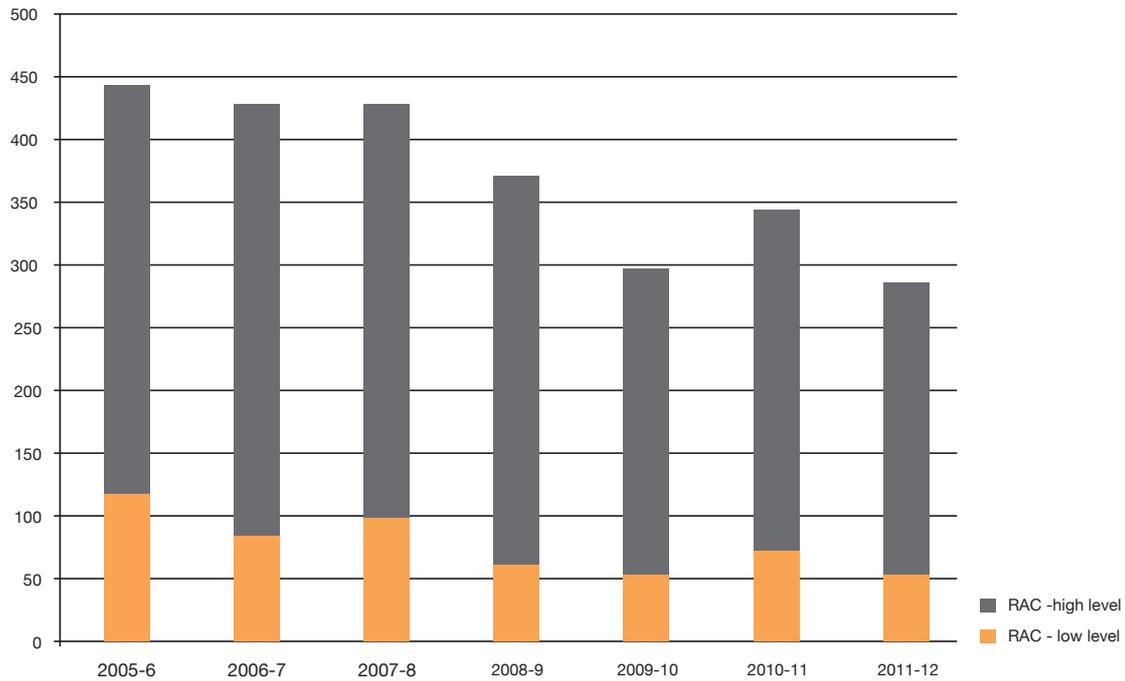
**Figure 4.3: ACAT assessments for people aged under 50 at referral by recommended long-term care setting, 2005 to 2012**



ACAT Assessment Recommendations for under 50 years

Figure 4.4 displays the number of RAC recommendations for people under 50 years. In 2005-06, RAC was the recommended long-term care setting from the ACAT for 443 people under 50. By 2011-12, 286 people under 50 had RAC as their recommended long-term care setting. Recommendations for placement of a young person to high level RAC showed a 29% reduction from 325 people under 50 to 231, while recommendations to low level RAC reduced by 53% from 118 people under 50 in 2005-06 to 55 people under 50 in 2011-12.

**Figure 4.4: ACAT assessments completed for people aged under 50 with recommended long-term care setting of RAC by state and territory, 2005 to 2012**



These trends are likely to be related to an increased awareness in the health and aged care sectors that RAC is not an appropriate option for many young people primarily generated by the YPIRAC initiative. This reduction may also indicate that more people returned to their previous home with supports or moved to other appropriate housing with support options.

Within Victoria, the Aged Care Assessment Service and Disability Services developed a protocol during the five year YPIRAC initiative which ensured that any younger person with disability referred to ACAT was identified to Disability Services<sup>39</sup>. Disability Services then had to explore the availability of appropriate alternative housing options prior to approval of a RAC placement.

A similar protocol is also described in the Aged Care Assessment Program Guidelines published in 2014 which have national application<sup>38</sup>. However given the unmet demand for support packages and housing across the disability system, many felt this was simply delaying admission to RAC. There is also anecdotal evidence that some people in this target group moved to services that did not provide the level of support they required, such as Supported Residential Services or boarding houses. For some people at risk of admission to RAC, boarding houses are likely to result in poorer outcomes than living in RAC.

### **Implications for Potential Solutions**

- There is a range of factors that lead to the admission of young people to RAC.
- We need a variety of strategies to prevent new admissions of young people to RAC.
- Aged Care Assessment Teams are less likely to recommend RAC for a person under 50 than they were a decade ago.
- Most (59%) young people are admitted to an acute or rehabilitation hospital before their first admission to RAC.
- Prevention of new admissions and the creation pathways from hospitals to the community requires collaboration between health and disability services.



## 5. Why is it hard to leave RAC?

Our research and discussions with young people in RAC and their families demonstrates that once young people are placed in RAC it is difficult for them to move out. Young people in RAC often lose skills and their social networks diminish over time. For some people, expectations diminish and young people and/or their family begin to think that institutionalised living is the only possibility. For others, because there is limited funding for support to live in the community they are forced into RAC. The move to RAC can result in the loss of their home so that if they do secure funding for support in the future they have no home to return to.

### Loss of skills

Young people have limited opportunity to practice everyday tasks in RAC which leads to a deterioration in their abilities. Skills that are often lost include the ability to go to the toilet, eat or transfer from a chair to bed independently. Staff in RAC either do not have the time to support young people to maintain these abilities or they do not see the maintenance of everyday living skills as a priority<sup>3</sup>.

*“Yes, he’s got the ability to do it [feed himself] but they just don’t have the time. It’s easier for them to come along if he’s not eating, to get a spoon and go glump, glump like that. Like an aged person.” Marty’s mother*

A sibling highlighted the facility’s inability to maintain her brother’s mobility, which resulted in health issues and reduced skills:

*“When the mobility got worse they realised that he couldn’t get to the toilet on his own. So rather than assist him when he presses the buzzer, they wanted him in aids – incontinence aids – to make their world easier...they would let him sit there all day in his aids so they can save a penny or two. Every time my mother goes in there, he’s wet.” Harry’s sister*

Some young people in RAC are able to describe the struggle to maintain their skills and independence while living in RAC.

*When Helen was assessed by ACAT for entry into RAC she was assessed without her wheelchair. The result was that she was assessed as being 'highly dependent'; the assessment noted that she could not brush her own teeth. Helen relies on her wheelchair to get to the bathroom. When she explained to the facility manager that she didn't need assistance to brush her teeth, amongst other things, the manager told her that it was important that her care reflected her assessment. Helen believes that this is to maximise the subsidies the facility gets from the government. Helen is battling to preserve her skills in a very disabling environment where institutional requirements and concerns around staff OH&S override the needs of individual residents. For example, Helen is expected to be in bed for 12 hours per day, she is not allowed to transfer herself from her chair to bed, or the toilet. The facility requires that she be lifted using a hydraulic hoist. As a consequence she has lost the balance required to sit on her bed unassisted. As she now requires assistance to go to the toilet, which is often difficult to get, she is encouraged to wear continence pads day and night. Helen's frustrated that she's not allowed to do anything for herself, she can't even make herself a cup of tea, as residents can't access boiling water. She explained that 'everything they do makes me more dependent. Everything they do makes it more difficult for me to be anywhere else but RAC.'*

### **Loss of social networks**

RAC facilities are not places that readily enable a young person to socialise with family and friends. As a result, young people in aged care facilities tend to receive fewer and fewer visitors as time passes and they lose the opportunity to grow socially with their peers.

*Holly aged 39 said, "My ex-boyfriend came down once. It wasn't very pretty though - like, my situation, my living quarters... I think the smell of faeces would have put him off".*

Many young people in nursing homes have told us of the difficulty of maintaining their relationship with their children while living in RAC.

*“Well the children were shocked to see their father amongst elderly people... it was just not a home environment. In some ways they were a little bit embarrassed for their dad. Just very, very unpleasant”. RAC Manager*

For some young people in RAC the difficulty of maintaining contact with family and friends is compounded by the location of the RAC facility.

*Rachel has always lived in Regional NSW. For 20 years she lived in her community, where she had many friends and an active social life. Two years ago, she experienced some difficulties managing her mental health condition, and was consequently admitted to hospital. A hospital social worker told her that if she did not accept an available nursing home placement some two hours away from her hometown, she would have to stay in hospital. Not wanting to spend a minute longer in hospital, and in her full capacity to make decisions, she agreed to this. She misses her family and neighbours, her visitors are limited by the large distance that must be travelled. Rachel wonders why there isn't an alternative arrangement for her, in her hometown. She acknowledges that she needs support to ensure medication compliance and complete household duties. She yearns to return to her hometown.*

## **Institutionalisation**

RAC facilities tend to be institutional environments with rules and rigid routines. Residents have limited opportunities to participate in household tasks or make everyday decisions. Some young people spend most of their day in their room and have few opportunities for choice regarding home and community-based activities. Young people in RAC are usually not able to step out their front door because of the security code required to leave most RAC facilities<sup>3</sup>.

Young people in RAC report that the institutional environment of RAC makes it hard to adjust to community living.

*Vicki lived in a RAC facility for just under four years. When she eventually left, she was confronted with the reality of her lack of independence. In the RAC facility, everything was done for Vicki, every choice was made for Vicki. What to eat, when to eat, when to sleep, when to get out of bed. This 'institutionalisation' in the RAC facility, led her to be ill equipped on return to the community. She had lost the ability to plan and structure her day as she was so used to being told what to do and when.*

*In her early 30's when she entered a RAC facility, Kate thought her life had ended. It hadn't, so she saw two options; she could either get so sick she would be returned to hospital, or she could end her life. Out of respect for her parents, she chose the former strategy. When she left the RAC facility she weighed 43 kilograms. It was with a mixture of elation and terror that she greeted the news that her social worker had found a place in shared supported accommodation for her. As much as she wanted to leave the RAC facility, Kate felt so institutionalised after her sixteen month "incarceration" that she seriously questioned the wisdom of moving out. The Kate of today is unrecognisable in comparison to the Kate in the RAC facility. She is delighted that she found the courage to move out.*

## **Funding for individual support**

Young people often remain in RAC because they cannot get access to the funding for the support they need to live in the community.

*Terry, aged in his early 50's lives with his brothers three days a week, where he cooks meals and is motivated to do things for himself. The other four days he spends in a RAC facility, where he waits out the days of routine and restriction in frustration, longing to be back with his family. Between support and therapy, the time Terry does spend at home exhausts his fifteen hours of funded support each week. Until he*

*can secure additional funding he has no choice but to spend four days of the week in the RAC facility.*

## **Loss of Housing**

Funding for the support that young people in RAC require to live the community will be addressed by the NDIS when the scheme is rolled out nationally in 2018-19. However, for some people 2018, will be too late.

*Jennifer lives in her own home, which she has modified to support her independence and accommodate her wheelchair. Jennifer has multiple sclerosis (MS) and has applied for 3 hours per day of assistance with personal care. She has not been able to secure the funding she needs for support and Jennifer is at risk of entering RAC. However to enter aged care she is required to sell her home to pay the Accommodation Bond. Selling her home would leave her stranded in aged care with no home to go to when she does get access to funding for support when the NDIS is rolled-out nationally from 2018.*

Some people with disability who enter RAC are unable to return to the community because they can't afford to keep their home in the community.

On July 1 2014 the Commonwealth's *Living Longer Living Better* aged care reforms came into effect. Central to these reforms was the adoption of the 'user pays' principle in Residential Aged Care (RAC) for individuals assessed as having means to contribute to the cost of their accommodation and care. These reforms have delivered more certainty for providers, and introduced transparency in relation to RAC costs for residents and their families.

Their requirement for resident with means, contributing to their accommodation and care may be good public policy in relation to the frail aged whose life expectancy, following permanent admission to residential aged care, is on average 28 months<sup>1</sup>. By contrast, for young people with a considerably longer life expectancy the policy is causing significant financial disadvantage.

The 2014 *Living Longer Living Better* aged care reforms are having a perverse impact on young people forced to enter RAC because they can't access the support they need in the community. The requirement for RAC residents to contribute to both the cost of their care, and accommodation, is resulting in people being forced to give up private rental or sell their homes to pay for RAC fees. Once they have given up their home in the community the barriers to young people exiting RAC are extremely high, and increase over time, as RAC fees deplete their financial resources.

Entry to RAC can result in loss of social housing, private rental or their own home. Once they lose their home, the dearth of accessible and affordable housing in Australia and their meagre income makes it impossible to find alternative housing.

#### **Implications for Potential Solutions**

- Once in RAC, young people lose skills and their social networks diminish.
- Young people in RAC can become 'institutionalised' in RAC which can make it harder to return to the community and regain independence.
- Some young people in RAC lose their home when they are forced to move into RAC which means they do not have a home to return to when they secure the support they need to return to community living.
- It is a much better use of resources to stop people from entering than letting them enter and then trying to move them out.

## 6. Impact of the National YPIRAC Initiative

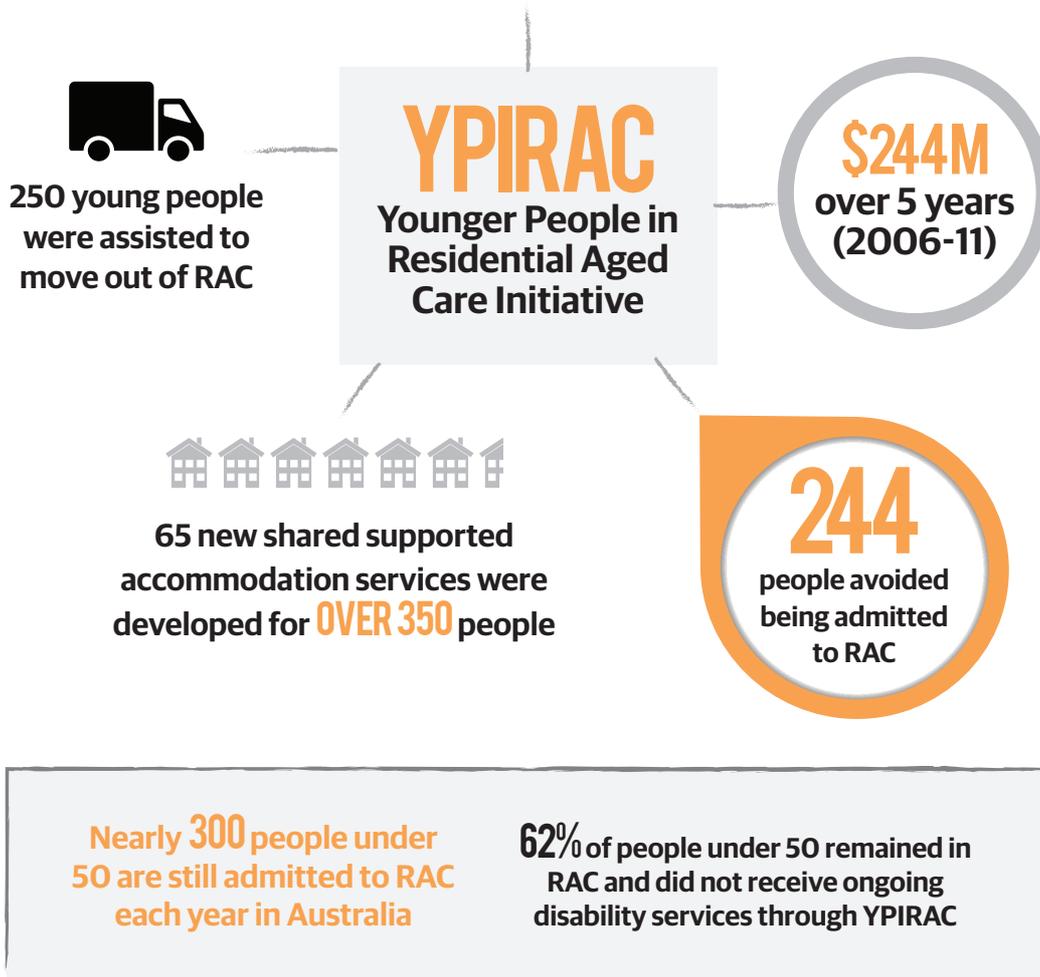
At its February 2006 meeting, the Council of Australian Governments (COAG) agreed that from July 2006, the Australian Government and the states and territories would work together to reduce the number of young people with disability in aged care. Governments jointly established and funded a \$244 million five-year Younger People with Disability in Residential Aged Care (YPIRAC) program. The program had three key strategic objectives:

1. To move younger people with disability currently in RAC into appropriate supported disability accommodation, where supported disability accommodation can be made available and only if the client chooses to move;
2. To divert future admissions of younger people with disability who are at risk of admission to RAC into more appropriate forms of accommodation; and
3. To enhance the delivery of specialist disability services to those younger people with disability who choose to remain in RAC if RAC remains the only available suitable supported accommodation option.

The initial priority of the program was people under 50 years of age. COAG determined that responsibility for day-to-day management of the program rested with state and territory governments and that implementation should take account of the individual circumstances applying in each jurisdiction. The state, territory and federal governments agreed on targets related to the reduction of the number of people under 50 in aged care and the number of people to be moved out of aged care during the five-year initiative <sup>40</sup> (Table 6.1).

*The National Disability Agreement (NDA), which replaces the Commonwealth State Territory Disability Agreement (CSTDA), came into effect on 1 January 2009. The NDA supersedes all previous bilateral agreements under the previous CSTDA, including the YPIRAC program. Australian Government funding for the YPIRAC initiative was rolled into funding provided to the state and territory governments for the NDA. However, YPIRAC targets set out in bilateral agreements remained <sup>40</sup>.*

People who moved went outside more often,  
had more opportunities to make everyday  
choice and spent fewer hours in bed.



## National Targets

At the national level, the agreed initial targets over the five-year life of the program were:

- Net reduction in the number of younger people with disability under the age of 50 in RAC of up to 689
- Up to 288 people under the age of 65 who are at risk of admission to RAC to be provided with services to divert them from inappropriate admission to RAC, and
- Up to 247 people under the age of 65 to be provided with enhanced services within a RAC setting where RAC is the only available, suitable supported accommodation option <sup>18</sup>.

## Net reduction

At a national level the program fell short of its “up to 689” net reduction target, achieving a net reduction of 349. From June 2006 to June 2011, the number of people aged under 50 fell by 35% (Table 6.1).

The numeric targets for each state and territory are shown in Table 6.1. The targets specific to the Northern Territory are unknown. The NSW Government did not provide a net reduction target. Most of the states and territories that provided a target for net reduction achieved the target apart from Queensland where the net reduction of 119 was just short of their 120-160 net reduction target.

**Table 6.1: Net reduction targets and outcomes of the YPIRAC initiative**

Targets and outcomes	NSW	Vic	QLD	WA	SA	Tas	ACT	NT	Australia
Target net reduction of people under 50 living in RAC <sup>18, 22</sup>	–	71-136	120-160	25-40	28-40	4-9	4	unknown	<b>Up to 689</b>
Number of people under 50 in RAC June 2006 <sup>45</sup>	391	221	244	65	60	15	<5	<10	<b>1,007</b>
Number of people under 50 in RAC June 2011 <sup>45</sup>	287	133	119	49	48	12	<5	<10	<b>658</b>
Actual net reduction	106	88	125	16	12	3	2	-1	<b>349</b>
Number of people accessing YPIRAC initiative 2006-2011 <sup>45</sup>	230	284	336	85	110	15	17	10	<b>1087</b>

## People moved out

Although some states did not achieve their target for the number of people to be moved during the YPIRAC program (Table 6.2), a significant number of new YPIRAC supported accommodation services were opened after 30 June 2011. In most states these targets were largely met by the 30 June 2012. However NSW services were still opening late in 2014. By December 2014, 65 new YPIRAC accommodation services providing housing and support for more than 350 young people either living in RAC or at risk of admission.

In Victoria, the capital cost (including land purchase costs) of these new YPIRAC services was \$250,000-300,000 per person for standard configuration 5-6 bedroom group homes. For unit developments and non-standard models of housing the capital costs were \$300-400,000 per person. In South Australia, the cost of six person clusters of units ranged from

\$1.2-1.6 million depending on the land cost. In Victoria the annual cost of supports for the YPIRAC services is estimated to be \$15 million per annum statewide<sup>3</sup>. The annual cost of support per person ranged from \$110,000-270,000 per annum. In NSW the support costs for YPIRAC accommodation services ranged from \$119,310 to \$165,000 per person per annum<sup>21</sup>.

**Table 6.2: Number of people moved out targets and outcomes of the YPIRAC initiative**

Targets and outcomes	NSW	Vic	QLD	WA	SA	Tas	ACT	NT	Australia
Target number of people to be moved <sup>18, 22</sup>	109-143	140	57-74	43	Up to 40	6	4	unknown	-
Number of people moved from RAC <sup>4</sup>	55	72	72	20	22	7	<5	<5	<b>250</b>
Number of new YPIRAC accommodation services developed by December 2014	34	22				1	1	0	
Number of places for people in the target group through new Accommodation services by December 2014	121	104	30	20	40	6	4	0	<b>325</b>

## People diverted from admission to RAC

At a national level the YPIRAC initiative only met 85% of the target of “up to 288” people to be diverted from RAC (Table 6.3). The number of people under 50 admitted annually decreased by 21% between 2005-06 and 2010-11. At a state level Victoria, South Australia and the ACT exceeded their targets, Queensland met their target and NSW, Western Australia and Tasmania fell short of their targets.

**Table 6.3: Number of people diverted targets and outcomes of the National YPIRAC initiative**

Targets and outcomes	NSW	Vic	QLD	WA	SA	Tas	ACT	NT	Australia
Target number of people to be diverted <sup>18, 22 21</sup>	47-60	60	60-80	30	23	6	4	unknown	<b>Up to 288</b>
Number of people diverted from admission to RAC <sup>4</sup>	14	69	70	27	41	4	12	8	<b>244</b>
Number of new admissions under 50 2010-2011 <sup>45</sup>	74	56	32	17	20	<5	<5	<5	<b>207</b>

### People remaining in RAC receiving enhancement packages

At a national level the YPIRAC program exceeded the target of up to 247 enhancement packages by 37%, with 338 young people living in RAC receiving additional disability services. At a state level, NSW, Victoria and Western Australia exceeded the targets set for enhancement packages, the ACT met their target and Queensland, South Australia and Tasmania did not meet the target. In Victoria the average cost of enhancement packages for community access, therapy, transport, recreation and leisure was \$10,000 per annum <sup>3</sup>. Individualised support packages funded through this program made a significant difference to the lives of many people. For example, it enabled some people in the target group to participate in age-appropriate activities and access their local community.

**Table 6.4: Number of people living in RAC receiving enhancement packages targets and outcomes of the National YPIRAC initiative**

Targets and outcomes	NSW	Vic	QLD	WA	SA	Tas	ACT	NT	Australia
Target for number of people to receive enhancement packages <sup>18, 22</sup>	65-100	40	50-60	10	28	18	4	unknown	<b>Up to 247</b>
Number of people who received additional disability services while in RAC (Group 3) Table A17 <sup>4</sup>	177	117	71	38	22	16	10	7	<b>456</b>

## Equipment

In Victoria alone, 114 YPIRAC participants received non-recurrent funding for assistive products and technology. Equipment funded included wheelchairs and accessories, walking frames, slide sheets, hoists cushions, commodes, beds, mattresses, overlays, recliner lounge chairs, over-bed tables, portable ramps, slings, communication devices, computers, call buzzers and adaptive switches.

The Victorian YPIRAC initiative funded over \$1.4 million for the supply of assistive technology and equipment, including associated administration, repairs and maintenance <sup>3</sup>.

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Like the enhancement packages, funding for the provision of equipment also made a significant difference to many lives. For example, wheelchairs with supported seating enabled some people to sit out of bed without discomfort and to go outside and access their local community. Funding for speech pathology and communication aids enabled some people to express their basic needs and preferences.

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One participant used his new communication device to articulate the difference it has made:

*YPIRAC funding "has given me the opportunity to communicate again with people...it's like going to bed a mute and waking up being able to talk and communicate again. My life has begun again as I can relate as an adult."*

## People who missed out on the YPIRAC Initiative

While the YPIRAC Initiative made a significant difference to the lives of the people living in RAC who received services, many people who were eligible for the program did not participate in the YPIRAC initiative or receive services. These people – particularly those who had no-one to advocate for them – received limited or no assistance and continue to lead impoverished and restricted lives in RAC facilities.

The number of young people in RAC who missed out on the YPIRAC initiative can be estimated by comparing the population of people under 50 in RAC in Australia with the number of participants in the YPIRAC program who received services. For example, in June 2010, there were 715 people under 50 living in RAC in Australia with only 313 people (56%) under 50 years living in RAC participating in the final year of the YPIRAC program (2010-2011). During 2010-11, 87 people under 50 moved to more appropriate supported disability accommodation. Of the YPIRAC participants living in RAC, 131 people under 50 living in RAC were already receiving disability supports and a further 54 people living in RAC received disability supports during 2010-11. Of the 715 people under 50 living in RAC in 2010-11 in Australia, an estimated 443 (62%) people under 50 remained in RAC and did not receive disability supports from YPIRAC (Figure 6.1). While a small percentage of people who did not access the program would have been ineligible (1.5%<sup>3</sup>) or decided not to participate (4%<sup>3</sup>), most of these people are likely to have missed out of services funded by YPIRAC due to their inability to respond to a written letter and no one to respond on their behalf.

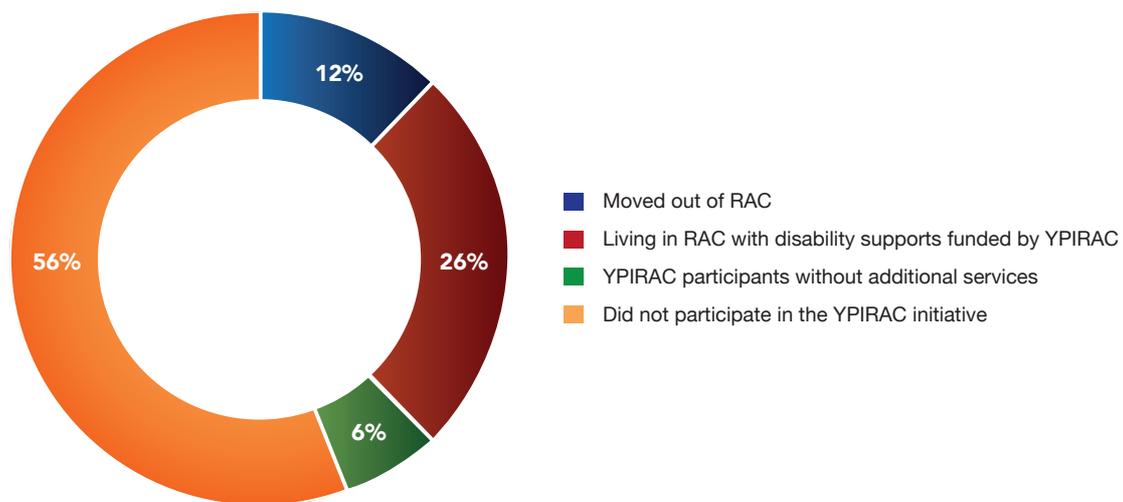
One key weakness in the approach to communication regarding the YPIRAC initiative used by most jurisdictions was the reliance on written communication to invite residents under 50 living in RAC to participate in the program. Some states followed-up the people who did not respond to these letters. In Victoria a phone call was made to the managers of RAC facilities. In Western Australia, follow-up involved visiting RAC facilities and face-to-face contact with potential participants.

Anecdotal evidence from aged care staff and service providers suggests that many of these letters were either placed in the bin or left unopened. Given the cognitive, communication and physical impairments experienced by this population, most young people in RAC are not able to deal with their correspondence independently and could not understand or

respond to these letters. Many people in the target group do not have anyone to respond on their behalf. Some family members reported that they did not respond initially because they did not understand the content of the letter. Face-to-face contact is required to give young people in RAC a genuine opportunity to make a choice about participating in a program <sup>22</sup>.

Recommendation 12 in the report stemming from the Joint Standing Committee review stated, ‘With the expansion of the trials in the Hunter and Barwon, it is important that the NDIA inform young residents in these [nursing] homes of their options under the NDIS. The committee believes that an information campaign could be put together to inform those young people living in residential nursing homes across all trial sites of the process for applying to become a participant with the NDIS’ (section 6.48, p.140-141).

**Figure 6.1 Total population of people under 50 in RAC in Australia and estimated proportion of people who did and did not receive disability supports funded by the YPIRAC initiative**



## Limitations of the YPIRAC Initiative

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An evaluation of the Victorian YPIRAC program by the Summer Foundation and Monash University found that moving out of RAC enriched the lives of young people with disability. They went outside more often, had more opportunities to make everyday choices and spent fewer hours in bed.

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However there were also a number of limitations to the YPIRAC program.

### Returning to live with family

Early in the initiative it was anticipated that given disability supports, a high percentage of young people would move out of RAC and return to their home. However, it was discovered that once young people have lived in RAC for some years, they are much less likely to be able to move back to live with family. One of the key findings from this initiative is the importance of preventing new admissions to aged care facilities, rather than assisting the person to move out to community settings after they have been admitted to RAC.

### Choice in housing and support options

People in this target group have a diverse range of support needs and preferences for housing and support. Most of the services developed through YPIRAC were a variation on a 'group home' model. A whole range of housing and support options needs to be developed and available for this target group. This would enable people to have real choice about where they live and make the best use of available resources. There also needs to be scope to develop options that are tailored to the specific needs of an individual and/or their family.

Developing the scale and range of housing and support options required to resolve the issue of young people living in or at risk of admission to aged care will require a whole of government approach with the housing and disability sectors partnering together to provide a greater range of options than currently available through either system.

## **Workforce issues**

Similar to the broader disability sector, some YPIRAC services are struggling to attract and retain quality staff. In comparison with other people receiving disability support services, people in the YPIRAC target group are more vulnerable and supporting them is more complex. Attracting and retaining quality staff, who are skilled and capable of providing a rehabilitative approach, as well as offering support and encouraging community engagement, is a significant challenge for providers. Support workers require additional training to manage the complex care needs of people in this target group. The creation and maintenance of a staff culture that treats people with dignity and respect is key factor in determining the quality of life of the people receiving services. Quality skilled staff are essential to enable people in the target group to have a basic standard of living and re-gain meaningful participation in community life.

## **Community inclusion**

Being in the community is not the same as being included in the community. Assisting people with severe disabilities to become part of community life is a challenging area of work that requires tenacity because relationships with people in the local community are not always spontaneously formed. A staff culture that is knowledgeable about how best do this and that supports and fosters community inclusion is essential.

## **Loss of focus on YPIRAC target group**

There is anecdotal evidence that some services developed through the YPIRAC initiative are losing their focus on their intended target group. Some YPIRAC services report that there is pressure from state disability services to fill vacancies with people with disability who have a housing crisis but are not in RAC or at risk of admission. There is a significant risk that over time some of the shared supported accommodation services developed through YPIRAC will become absorbed into the generic state disability service system, and house people with differing, incompatible, and varied needs, who are not part of the YPIRAC target group. This may lead to the overall loss of places suited to the YPIRAC group and more young people will be admitted to live in RAC.

In Victoria the Summer Foundation and Karingal co-ordinate a YPIRAC Accommodation Services Providers network that meets twice a year to assist providers to retain their focus on the YPIRAC target group, and provide opportunities for networking and for specialist professional development. With the transition to the NDIS over the coming years, there is a need to ensure that the new system retains the specialist knowledge and practices built into the YPIRAC models.

### **People currently receiving YPIRAC funded services**

The national YPIRAC program concluded in June 2011. Ministers across all jurisdictions committed to maintaining effort consistent with the objectives of the program <sup>41</sup>. The understanding at the end of the initiative was that all individuals receiving ongoing YPIRAC services would continue to receive support as long as it is required. Given that it has been over three years since the YPIRAC initiative concluded, it would be useful to understand the current impact of this initiative on the lives of young people in RAC. The following questions could determine the ongoing effectiveness of the YPIRAC initiative and the annual level of funding that is still allocated to the YPIRAC target group in each jurisdiction.

### **Enhancement packages**

In 2010-11, 338 YPIRAC participants remained in or entered residential aged care with additional disability support services <sup>19</sup>.

- How many original YPIRAC participants continue to receive an enhancement package in each state and territory?
- How many YPIRAC participants who received enhancement packages have since died?
- How many enhancement packages have been repurposed for other young people living in RAC?

## **Diversion packages**

During the YPIRAC initiative, 244 people were diverted from aged care <sup>19</sup>.

- How many original YPIRAC participants continue to receive a diversion package in each state and territory?
- How many people who received diversion packages have been admitted to RAC?
- How many YPIRAC participants who received diversion packages have since died?
- How many diversion packages have been re-purposed to prevent new admissions to RAC?

## **New shared supported accommodation services**

During the YPIRAC initiative, 250 people were moved out of aged care <sup>19</sup>.

- Have all shared supported accommodation services funded through YPIRAC opened?
- How many original residents in YPIRAC shared supported accommodation services have moved to more independent living options?
- How many original residents in YPIRAC shared supported accommodation services have died?
- How many original residents in YPIRAC shared supported accommodation services have moved to RAC?
- How does each state and territory ensure that these services continue to house people in the YPIRAC target group?
- What are the criteria for new residents in these services?

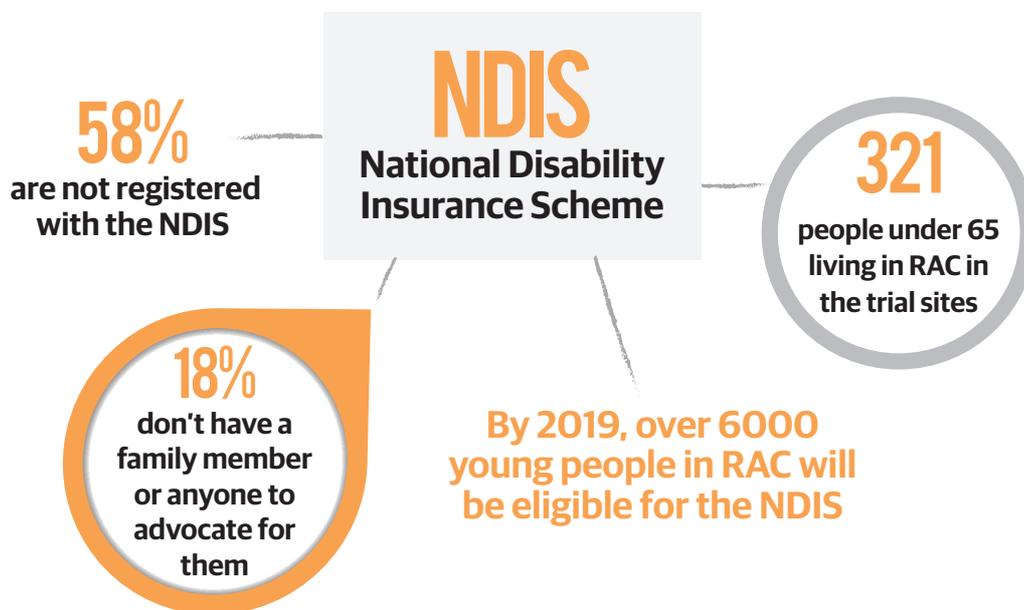
### **Implications for Potential Solutions**

- 62% of people under 50 remained in RAC and did not receive ongoing disability services through YPIRAC.
- Future programs need to be proactive in finding young people in RAC and provide face to face contact to support them to engage.
- Since the YPIRAC initiative ended, the system has largely reverted to the way things were in the past.
- The new housing and support options are full and vacancies are usually only created when a resident dies.
- No one sector has the expertise or resources to prevent new admissions of young people to RAC or to develop the range and scale of housing, rehabilitation and ongoing support required for this target group.
- The complex needs of young people in RAC requires a more co-ordinated approach that involves health, housing and aged care rather than just looking to disability services to solve the issue alone as has happened in the past.



## 7. What difference will the NDIS make?

The National Disability Insurance Scheme is a no-fault social insurance scheme for people with severe or profound disability <sup>42</sup>. The NDIS will provide the reasonable and necessary supports that people with disability need to live ordinary lives and make progress towards their goals. The NDIS was launched in four jurisdictions on 1 July 2013, with a further three starting on 1 July 2014. Nearly half a million Australians will be covered by the scheme when it is fully operational in 2019.



*The NDIS promises once-in-a-lifetime disability reform to an inequitable, underfunded, fragmented and inefficient disability service system<sup>24</sup>. The National Disability Insurance Agency has been established to implement the NDIS.*

*The NDIS is a massive and complex reform<sup>43</sup>. Unlike the existing disability service system in Australia that is largely a welfare-based and rationed model where people with disability are passive recipients of block-funded services, the NDIS is a market driven system based on rights where people with disability are empowered to make choices regarding services and supports. The NDIS aims to provide individualised person-centred processes where people with disability have choice and control over the supports and services they need to make progress towards goals. People with disability will also have choice regarding who provides their supports and how they are delivered, the extent to which they manage their own funding and the level of risk they take in organising their lives.*

*On 1 July 2013, the NDIS began in Tasmania for young people aged 15-24 years, in South Australia for children aged 13 and under (on 1 July 2014), and in the Barwon area of Victoria and the Hunter area in NSW for people up to 65 years. From 1 July 2014 the NDIS commenced across the ACT, the Barkly region of Northern Territory, and in the Perth Hills area of Western Australia. Roll-out of the full scheme in NSW, Victoria, Queensland, South Australia, Tasmania, the ACT and the Northern Territory will commence progressively from July 2016. The NDIS will be fully implemented across Australia in 2018-2019<sup>44</sup>.*

## **What does the NDIS mean for young people in RAC?**

People under 65 years of age living in RAC are eligible for funding through the NDIS. The NDIS is an essential part of the solution to the issue of young people being placed in RAC, as it will provide the crucial funding for support that young people in RAC or at risk of entry need to live in the community. However, the NDIS cannot on its own stop the inappropriate placement of young people in RAC<sup>3</sup>. Two other elements are required.

1. More accessible and affordable housing needs to be built.
2. The system needs to change to prevent new admissions.

For example, people with catastrophic brain injury need slow stream rehabilitation services that give them the time they need to demonstrate their potential before they are forced into RAC.

Ideally the implementation of the NDIS will be accompanied by the development of systemic change and an increase in service options that enable people with severe brain injury and other disabilities to maximise their independence and potential. Unlike the current crisis driven and reactive disability service system <sup>10</sup> that is also subject to rationing and wait lists, the scheme will provide early intervention and pre-emptive support to minimise the impact of disability on individuals and their families.

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**Targeted support will enable people with disability to lead the ordinary lives that the rest of us take for granted, with real participation, real social relationships and a valued place in mainstream society.**

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The aspiration is that the NDIS will, by developing a more effective and better funded disability support system, support people to develop their full potential and live a life that is as independent and fulfilling as possible for them. At the same time NDIS aims to deliver an overall long-term economic benefit to the community through supporting people with disability and enabling them to be active citizens. However, the positive impact of the NDIS will remain limited if there is no significant increase in the availability of affordable and accessible housing across all communities. The lack of affordable and appropriate housing options remains a major obstacle to people with disability being able to maximise their independence and have greater choice and control over their lives, even with the additional resources available through the NDIS.

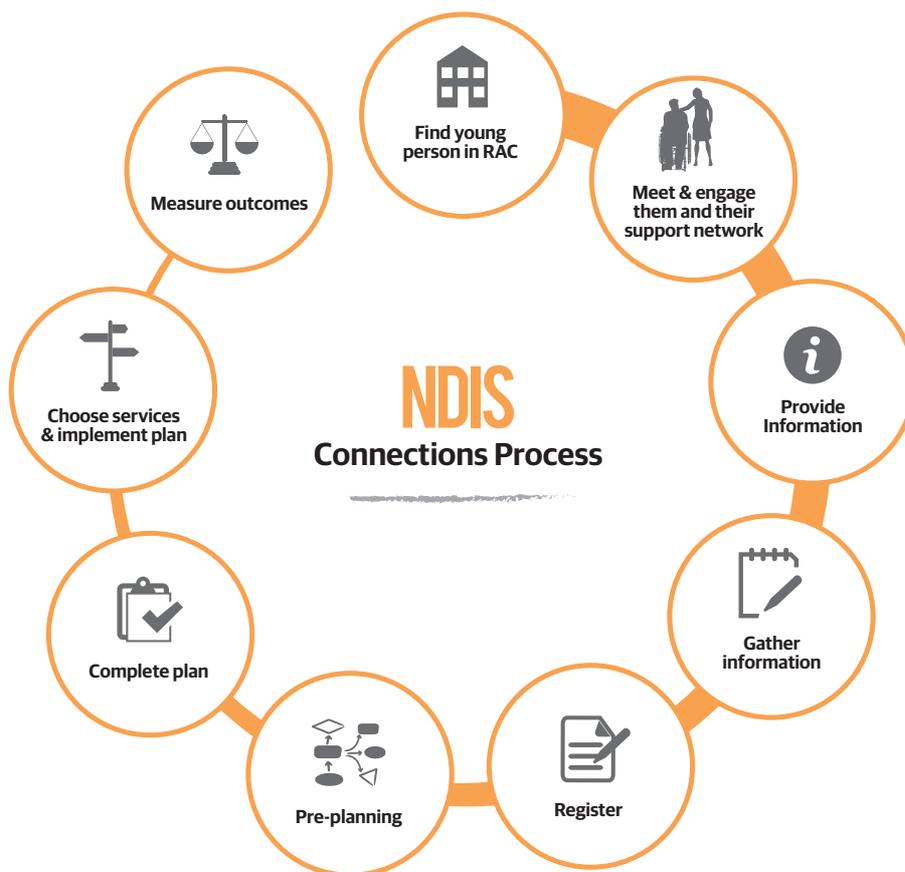
There are around 410,000 people who will receive funded support through the NDIS. An estimated 255,000 of these people are aged 25 to 64, and between 154,000 and 193,000 are on low and very low incomes <sup>45</sup>. The 6000+ young people who are currently in residential aged care across Australia are expected to be clearly eligible as part of these figures.

## **NDIS Connections Project and Action Research**

Not everyone has equal access to funding from the NDIS. There are currently 321 people under 65 living in RAC in NDIS trial sites who are eligible for funding for services and equipment through the NDIS. Many young people in RAC and their families do not realise that they are eligible for services and equipment funded through NDIS. Most of these people will not receive funding unless someone goes out to find, inform, engage and support them through the NDIS registration and planning process.

In February 2014, the Summer Foundation commenced the *NDIS Connections* project to find young people in RAC in the Hunter NDIS trial site and support them to register, plan and implement their plan. In May 2014 this program was extended to the Barwon NDIS trial site. In each trial site one worker is currently employed 0.8 FTE. This program is funded through philanthropic grants from the Ian Potter Foundation and the RE Ross Trust. In the Hunter NDIS trial site there are 149 people under 65 living in RAC, 26 of whom are under 50 years old. In the Barwon NDIS trial site there are 82 people under 65 living in RAC, 7 of whom are under 50 years old (Appendix A).

The *NDIS Connections* project officers work cooperatively with the NDIA, RAC staff, families, friends, and service providers. Workers visit RAC facilities in the NDIS trial sites to proactively find people under 65, provide information about the NDIS and then support them and their families to engage with the NDIS. They support them to gather the information and complete the registration process, prepare for their planning meetings and support them as they choose services and implement the plan. Workers also link young people who are currently in RAC to opportunities for alternative housing and support.



So far the NDIS Connections program has found and informed 58 people about the NDIS, supported 29 to register, supported 27 people to plan and 24 people to implement their plan. The work required to support this group to participate in the NDIS has been more time intensive than anticipated. The person with disability often has a limited ability to participate in decision-making or provide consent due to their cognitive and communication difficulties. Their social networks may be either complex or virtually non-existent.

Most young people in RAC have someone appointed to manage their finances but do not have a formal guardian to make other decisions. Often the individual's ability to participate in decision-making is unknown. Young people in RAC rarely have an up-to-date Speech Pathology or Neuropsychology assessment to provide insights into their communication or decision-making ability. Sometimes there is a family member who effectively makes decisions on behalf of the person with disability but more often there is no-one to make decisions or provide consent or the information required for the registration process.

The *NDIS Connections* project also involves action research. Preliminary findings indicate that 18% of young people in RAC do not have a family member or anyone to advocate for them and 58% are not registered with the NDIA (Appendix B). The data collated will provide an evidence base to work with the NDIA to identify and change some systems and processes to make the registration and planning more efficient for the young people in RAC target group. We will also continue to identify and develop practical resources to build the capacity of young people in RAC, their families and workers.

## **Outcomes in the NDIS Trial Sites**

It has been 18 months since the NDIS trial sites commenced in the Hunter and Barwon regions. There are a limited number of NDIS participants in RAC that have been receiving services long enough to be able to report on outcomes. Most of the young people in RAC that the Summer Foundation is working with are still in the process of registration or planning.

In the Hunter trial site one young person has moved from RAC to a group home. In the Barwon trial site one young person has moved back to the family home to live with her husband. We do not anticipate that many young people will move out of RAC in the trial sites due to the limited number of appropriate housing and support options. We are aware of two people living in the Barwon NDIS trial site who avoided admission to RAC through the provision of funding for additional supports. A number of young people living in RAC have received funding through the NDIS. The provision of relatively small packages of funding has made a significant difference to their lives.

One NDIS participant living in RAC has MS and experienced considerable discomfort and distress using a standard shower chair. Providing personal care while the participant was distressed was also a significant challenge for RAC staff. The provision of a shower commode chair has significantly improved the participant's experience of daily personal care.

Another NDIS participant received weekly visits from family in RAC but rarely went out into the community. The NDIS has provided funding for 10 hours of support for community access per week and a contribution to taxi fares. The participant now engages in regular activities in his local community. Regular access to the community has made a huge difference to his quality of life.

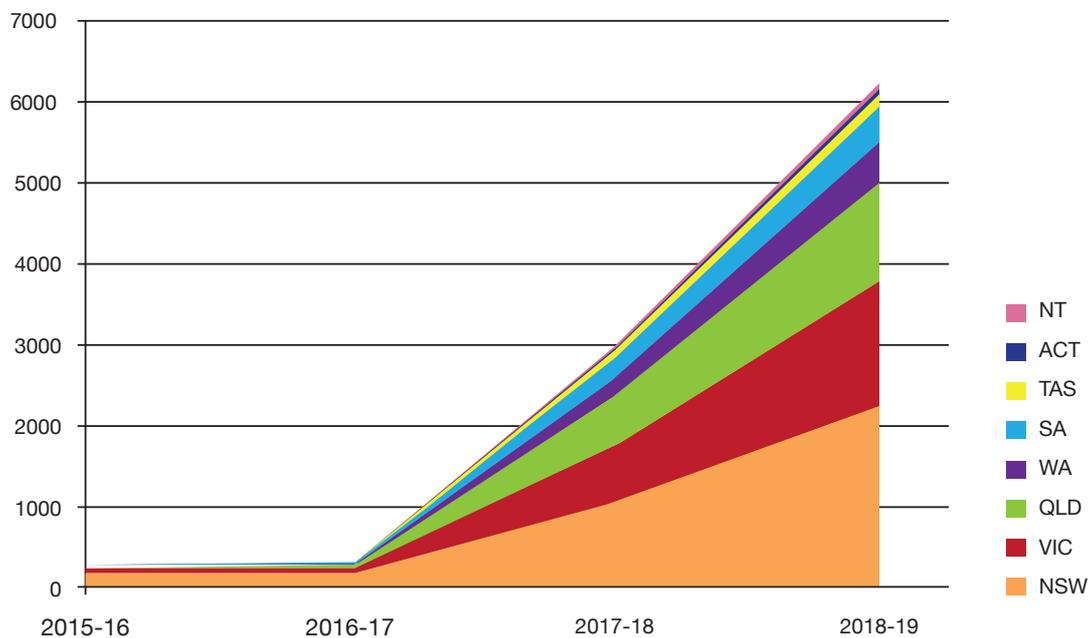
A high priority for another participant is visiting his daughter in her home. Given that there is no accessible public transport for the 70km journey, his only option is taxi transport. The cost of this taxi fare is prohibitive. The provision of a taxi transport allowance has enabled this participant to spend time with his daughter on a regular basis.

In the Hunter Region we are aware of 16 young people who were already in receipt of services funded through YPIRAC. Most of these people have made the transition to the NDIS and seem to be receiving similar services to those funded under the YPIRAC program.

### **Rollout of the NDIS: 2016-19**

As the NDIS is rolled out nationally from June 2016 to July 2019, there will be a further 5,888 people under 65 in RAC in Australia eligible for the NDIS (Figure 9.1). The Summer Foundation is in the process of developing partnerships including collaboration with the NDIA to scale the NDIS Connections program to a national level from 2016 to 2019. A strategy, involving workshops, will be developed to scale this 'case finding' work to reach all 3,000 people under 60 in RAC in Australia by December 2019. Although this program requires considerable resources, it is a one-off project to ensure that young people who are already living in RAC receive the support and equipment they desperately need to build better lives. This project, alongside a proactive program to prevent new admissions of young people into RAC will go a long way to addressing the needs of young people in RAC in Australia.

**Figure 9.1: Estimated number of people under 60 in RAC eligible for the NDIS 2015-19**



This work will involve workshops in each jurisdiction to provide information and build the capacity of young people in RAC and their families to participate in the NDIS. Most of the resources will be used to visit RAC facilities to find young people and support them through the registration, planning and implementation process.

#### **Implications for Potential Solutions**

- People under 65 in RAC are eligible for funding through the NDIS
- The NDIS is one part of the solution to the issue of young people in RAC – it will provide the crucial funding for support that this target group need to live in the community
- Most young people in RAC will not benefit from the NDIS unless someone finds, informs and supports them with the registration and planning process.
- 65% of people under 65 living in RAC are not receiving any disability support services
- Capacity to engage in goal setting and planning is often hampered by limited knowledge of the possibilities of life beyond RAC
- We need to develop resources to build the capacity of young people in RAC (and their families) to actively participate in the planning process.

Few things are more fundamental than having somewhere to live, to be as independent as possible, maintain connections with family and friends and access a range of opportunities in the local community. Having little or no choice about where you live or who you live with has a profound impact on mental and physical health and the ability to participate in community life. Yet this is precisely the experience of many people with disability who are living in RAC.

People with disability experience multiple challenges gaining access to appropriate and affordable housing <sup>46</sup>. The AIHW <sup>47</sup> found that people with disability tend to be concentrated in the fringe and outer suburban areas where housing costs are lower.

There is a chronic shortage of well-located, affordable housing for people with disability, particularly for those with high and complex needs, and those who need accessible and adaptable housing design. There is a critical need for new housing options that are close to shops, services and public transport, both from the point of view of easy access but also because people with disability are disproportionately on low incomes. But such well-located housing is often relatively expensive or not designed for people with disability and mobility impairments <sup>48</sup>.

There are limited opportunities for people with disability to participate in the mainstream housing market because of their low rates of employment and therefore limited purchasing power <sup>46</sup>. This group often lacks the capital to establish a deposit and the income to service a mortgage. Rental housing is often inaccessible to people with disability, both because of the high cost of renting privately and the physical characteristics of the housing stock <sup>48</sup>.

Central to including people with disability in the mainstream of society is providing a stable living environment (both housing and support) and moving away from a crisis response to addressing accommodation, services and support needs <sup>48</sup>.

The Productivity Commission's report on Disability Care and Support <sup>24</sup> identified an overall lack of housing options for people with disability. This shortage is particularly severe for those with profound disability and complex needs who require supported and accessible housing. For this group there are limited models and significant shortfalls in supply, with options for those requiring near 24-hour support and/or monitoring usually limited to RAC, living with parents, or living in group homes or community residential units (commonly called 'shared supported accommodation' in the disability sector). This predominant group living model limits choice in where people live, with whom they live and how they live.

For the past 20 years, the group home (referred to as 'shared supported accommodation' in most jurisdictions) has been the dominant disability housing model for people with more complex support needs. In this model people are to live with four or more people with limited privacy. We know that while group homes may work for some people with disability, they do not work for everyone. Research and consultation with young people in RAC or at risk of entry to RAC has strongly indicated the desire for a wider range of living options than traditionally available.

More contemporary models of housing and support are needed that support an individual's ability to have greater choice and control over how they live. Many young people in RAC acquire their disability as adults; 46% are in partner relationships and 27% are parents of school-aged children. Most existing models of housing and support for people with significant disability do not work well for people with families and most are not well integrated within mainstream housing. Many people who have acquired their disability as an adult want to live in their own homes as they have experienced independent living prior to their disability.

Many people with high and complex support needs who require access to 24 hour support and/or monitoring are not on public housing waiting lists. This is because of the complexity of sectors working together to meet housing and support needs. Improved planning and co-ordination across government services is an essential part of the process to align available and suitable housing with approval of individualised disability support funding, funding for equipment and ongoing rehabilitation, as necessary.

The launch of the NDIS is a significant part of the solution to resolving the issue of young people in RAC.

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The NDIS will provide funding for the support and equipment that people with disability need to live in the community. However, people need somewhere to live.

The NDIS has limited funding for capital to build new housing and it is not expected that many young people will move out of RAC as a result of the NDIS on its own. Australia desperately needs more housing that is both accessible and affordable.

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Provision of housing for people with disability should be viewed as a mainstream housing issue. The housing needs of people with disability should be an integrated part of national and state urban and housing planning strategies. These strategies need to recognise that many people with significant disabilities are on low incomes and need access to secure affordable rental housing. However, there are also likely to be people with disability who have access to some financial resources that would enable them pursue partial or full ownership options.

The ten-year National Disability Strategy <sup>49</sup> focuses on the need to improve the provision of accessible and well-designed housing, which offers security of tenure and choice for people with disability about where they live. A key area for action identified in this Strategy is to develop innovative options to improve affordability and security of housing across all forms of tenure for people with disability.

## Essential elements of housing for young people in RAC

Stable, quality housing is essential to bringing young people in RAC back into the mainstream of society. Following are the aspects considered essential to future housing and support options for young people in RAC:

Location: Proximity to shops, transport and other services is critical to enabling people with disability to easily get out of their home and have a meaningful life. Being located near family and friends and living in a familiar neighbourhood is also essential for maintaining relationships and community inclusion.

Range of housing options: Young people in RAC are a diverse group; they need a range of options to meet their needs, preferences and family circumstances.

Physical design: Accessible design that is adaptable to the diverse needs of this group is essential in order to maximise independence and community inclusion and reduce life-time care costs.

Technology: Advances in technology provide the potential for increasing independence and autonomy, and decreasing reliance on paid supports. Mainstream smart home and communications technology can provide cost effective solutions that enhance independence, let people with disability alert others when they need assistance and remotely monitor a person's safety and wellbeing, if required.

Individualised and flexible supports: Supports should assist people to develop as much independence as possible, build people's capability to live more independently and encourage and facilitate building a life that is meaningful and satisfying. Support approaches need to be tailored to the individual's needs and flexible enough to respond to changing needs, abilities and preferences. Many people with disability and their families have learned to live with very low expectations. Support providers often need to focus on building capacity and enabling people to have bigger dreams and a meaningful life <sup>50</sup>.

As many young people in RAC have complex support needs, skilled support is essential to enable them to transition successfully to more independent housing options. Past support models, expectations and practices brought from RAC and shared supported accommodation can impede their ability to benefit from more independent housing options.

Community belonging: Housing and support options should maximise opportunities to build and maintain relationships with spouse, family, friends and acquaintances and build new connections <sup>50</sup>.

The launch of the NDIS is a significant part of the solution to resolving the issue of young people in RAC. The NDIS will provide funding for the support and equipment that people with disability need to live in the community. However, people need somewhere to live.

### **Integrated housing and support projects**

There are a number of housing projects underway that involve the co-location of apartments for people with high support needs. These projects demonstrate models embedded in ordinary new apartment developments across the public, social and private housing sectors. They all incorporate accessible and adaptable design, and technology to support increased independence in daily living while ensuring the safety of people with complex disabilities. These models demonstrate that new housing opportunities can be created for people with high support needs in mainstream housing developments.

The following housing projects all provide examples of new housing options for people with high and complex support needs that are consistent with the principles underpinning the NDIS. The tenants of these projects have normal tenancy rights and responsibilities, just like their neighbours.

These examples are the result of collaborative approaches across different organisations. Between the projects all the major housing sectors are engaged. Two projects involve private developers who have been prepared to look at how their developments can contribute to increasing housing options for people with significant disabilities. Another project involves a community housing organisation, while a government housing authority is involved in the first project outlined.

## **The Square Woodville West Project, South Australia**

The South Australian Government through its housing division has redeveloped an old social housing estate - The Square Woodville West project. The first stage of this redevelopment included an apartment block of 30 units that was developed with a contribution from the Commonwealth Housing Affordability fund. Seven units in this block (on three different floors) have been designated for people with disability and complex support needs and have been designed to be fully accessible. They have a range of technology to support greater independence and safety.

SA Disability Services identified the tenants for these properties and provided funds for their support. SA Housing manages the units and each person has a tenancy agreement with SA Housing. An eighth unit has been allocated to provide the base for a 24 hour concierge service that is available to support tenants with the technology and respond to unplanned needs for assistance. The concierge service works to support people's independence and decision making in ways that complement their individual support arrangements.

This project represents a collaborative initiative between a state government housing authority and state government disability services, with a non-government organisation providing ongoing personal supports to tenants including the after hours concierge service.

*Link to further information: <http://www.dcsi.sa.gov.au/services/latest-news/media-releases/smart-living-apartments-give-people-with-disability-more-independence>*

## **Cairo Southbank, Victoria**

In Victoria a new model has been funded through the Commonwealth Shared Accommodation Innovation Fund (\$4.1 million capital funding) where 10 units will be purchased within a larger privately developed inner city apartment building for people with severe and profound disabilities (the Cairo Project in Southbank). Haven, a registered housing association will be responsible for the properties and managing the tenancies. Victoria's Disability Services will identify tenants for these properties through their disability vacancy management system, and will provide funding for support. In this model there will be onsite support services enabling flexible and responsive provision of individual support. Support will be co-coordinated through Scope, a large disability support provider.

Link to further information: <http://www.ypinh.org.au/key-reforms-and-initiatives/cairo>

### **Abbotsford Housing Demonstration Project, Victoria**

In 2013 the Summer Foundation launched its first housing demonstration project. This project has six accessible apartments for people with high support needs peppered throughout a 59 unit mixed private and social housing inner city development in Melbourne. The Summer Foundation purchased two apartments for young people at risk of or in aged care facilities. The Transport Accident Commission (TAC) clients tenant the other four accessible apartments.

This housing is centrally located, within 500 metres of a train station and shops. This maximises independence and inclusion and minimises transport costs and reliance on paid support staff. Use of home automation technology and communication technology allows tenants to alert staff of unanticipated needs for assistance. There is a small staff office that provides a hub for support staff on site 24 hours a day.

The establishment of this project was the result of close collaboration between the Summer Foundation, the Transport Accident Commission and Common Equity Housing Ltd, a Victorian Registered Housing Association. Annecto was selected as the support provider, and their skilled staff team individually support the tenants to make the most of the accessible features of the housing, the technology and the good access to the local community. This assists the tenants to maximise their independence and engagement with the many 'ordinary' opportunities available in the community.

Initial findings from Monash University research shows that all tenants increased their level of home, social and economic participation at 6 and 12 months after moving into their apartments. Tenants had more opportunities to make everyday choices. Their number of life roles (e.g. homemaker, family member, student ) either remained the same or increased. Tenants reported increased participation and levels of independence in meal preparation, shopping and organising social events in their new home and community, compared with their baseline setting. They attributed this change to the excellent location of their housing, (near accessible public transport, shops and recreation services) as well as the increased home participation as a result of living in their own home. The support received from a

Community Inclusion Facilitator was also seen as key to planning their transition, testing out new life roles and developing community links in their new neighbourhood. Some issues with the capacity of direct support staff were identified, including challenges in attracting and retaining a consistent team of workers over time.

*Link to further information: <http://www.summerfoundation.org.au/wp-content/uploads/Summer-Foundation-Housing-Brochure.pdf>*

### **Hunter Housing Demonstration Project, NSW**

The Summer Foundation is in the process of purchasing ten fully accessible apartments for people with significant disability in the Hunter NDIS trial site, and one smaller apartment for support staff. These apartments are peppered throughout a five-storey development that has over 100 units for private sale. The Summer Foundation has worked closely with the developer at the design stage to ensure that all 10 units, parking, lifts, common area doors and the building security system will meet the needs of people with disability. Structural support for the installation of hoists will also be incorporated into the build.

Apartments will incorporate two way communications technology and capacity for smart home technology. Via a smart phone or tablet, residents will be able to operate features such as lighting, blinds, cooling and heating, external doors and doorbell functions, as well as contacting support staff when needed. Residents will be able to maximise their independence and privacy while still having access to 24-hour on-call support. The Summer Foundation will be working closely with the local community, people with disability and their families, NDIA and government to develop this innovative demonstration model of housing and support which is due for completion by December 2015.

The Summer Foundation is planning to secure a third of the cost of this \$6.4 million project from the government. We have also been working with the NSW Government to secure unused National Rental Affordability Scheme (NRAS) allocations. The remainder of the project will be funded by a combination of philanthropy and social investment.

Success of the Hunter Housing Demonstration project will be demonstrated by:

- *Tenant outcomes*: empirical data regarding improved quality of life, social inclusion, increased independence, decreased reliance on paid supports and reduced life time care costs
- *Replication*: Reports to assist others to replicate this model for both young people in aged care facilities and other people with disability
- *Social finance*: demonstration of a model of social investment for housing for people with disability that is replicable and scalable.

Through the Abbotsford and Hunter Housing Demonstration projects the Summer Foundation aims to provide hard evidence regarding the cost benefits of investing in good quality housing for people with disability.

The fact that these projects are already in place, or the planning for them is well underway, indicates the real commitment there is for developing new approaches to housing for people with disability. It also demonstrates the potential for new options such as these becoming the norm for many people with significant disabilities. The general community also benefits from these models as they enable people with disability to be active citizens and make their contribution to society. People with disability no longer have to dedicate their energies to managing in housing arrangements that do not meet their needs.

## **Building an Evidence Base**

### **Evaluation**

Outcome studies from the first Summer Foundation housing project provides insights into the impact of well-located, accessible and adaptable housing in combination with technology, appropriate equipment and support approaches. Early findings from this research indicate that these models of housing and support will increase independence, reduce long-term care costs and improve wellbeing and quality of life.

Monash University and the Summer Foundation are completing a range of studies to evaluate the outcomes of housing and support options for people with high and complex needs. This research focuses on the outcomes for tenants, costs and post-occupancy evaluation of the built environment. The research will be extended to new housing sites

nationally, as they are established, in order to build an evidence base of the built and technology design principles, and impact of a range of housing and support models on outcomes of young people with complex needs.

### Knowledge Translation

The Summer Foundation is partnering with a range of organisations to document, translate and disseminate the knowledge generated through our housing demonstration projects. Sharing this knowledge is critical in assisting other organisations and government to replicate similar models of housing and support.

We also seek to influence state and federal government departments making decisions regarding regulation and funding that increases the scale and range of disability-specific social and public housing.

### Report on the development of the Abbotsford housing demonstration project

A report on the knowledge generated from the development of our first housing demonstration project will be available by the end of April 2015. An independent researcher was engaged to interview key stakeholders involved in the development of the Abbotsford Housing Demonstration project including the developer, housing provider, disability service provider, Summer Foundation staff, Transport Accident Commission involved in the implementation of this model of housing and support to gather the key learnings for other organisations interested in replicating this model.

### Video showcasing smart home technology and virtual tour

Our first housing demonstration project generated a great deal of interest from government, disability service providers, community housing providers and the National Disability Insurance Agency. Over 100 people had a tour of our first apartments prior to tenants moving in. Now that tenants have moved in to these apartments, they are their homes, and tours are no longer appropriate. A [virtual tour](#) of an apartment is available online so that people can explore each room and the design features to learn from our project. We also have produced a short [video](#) that demonstrates the communications, monitoring and smart home technology incorporated into the apartments. The video and virtual tour were funded by the Macquarie Foundation. We are currently seeking philanthropic funding to produce similar videos for our second housing demonstration project, which will showcase the next generation of smart home and communications technology.

## Hunter Housing Demonstration Project Design and Technology Report

The Summer Foundation will document the design principles of this project including detailed specifications for the build design, fit out and technology developed to create a stand alone report for use by housing providers, disability providers, government and funders interested in replicating the design features in these apartments.

### **Replication and scaling up new housing options**

The new housing models outlined previously are demonstrating new types of housing options that provide a viable alternative to RAC. The challenge is to move from having a small number of pioneering projects to having these more widely available.

There are basically two major challenges in doing this:

- Funding for capital development
- Urban planning and housing design

### **Funding for capital development**

The NDIS is being introduced at a time of high levels of unmet need for affordable housing across Australia and lack of any comprehensive strategy at the national or state levels for increasing the supply of housing to respond to the needs of people on low incomes. The recent cessation of provision of new incentives through the National Rental Affordability Scheme (NRAS) withdrew the last major funding source to stimulate development of housing for people on moderate and lower incomes. Without the injection of significant government funding support to stimulate and subsidise the development of new housing options for people on low incomes (which includes many people with disability supported through the NDIS) the opportunities for people with disability to live in housing that is well located, affordable, secure and supports their connection with the community will remain very limited.

There has been ongoing anticipation that the NDIS may provide up to \$700,000 million per annum funding for housing related costs for NDIS participants once the scheme is fully operational in 2019. This has the potential to provide much needed stimulus for new housing development for people with disability. However, given the delays in release of a

discussion paper on this funding, its potential to stimulate new housing options for people with disability is still unclear.

The Productivity Commission included a 'user cost of capital' in its model to meet the demand for housing generated by participants in the NDIS. Their access to supports may be addressed, but this will not achieve the hoped for outcomes if housing supply remains unaddressed. The inclusion of capital costs in packages for people with very high supports needs (around 28,000 people - 6% of participants) was estimated to be 12% of their costs. While this was costed, it was notional and not allocated. In the NDIA's current operational guidelines, the NDIS is responsible for 'user costs of capital in some situations, where a person requires an integrated housing and support model and the costs of the accommodation component exceeds a reasonable contribution from individuals'<sup>i</sup>.

In practical terms this is estimated at around \$550m per annum (in current dollar terms) for the 'user cost of capital' at full scheme. While this may seem a large amount, to achieve sufficient impact it needs to work as a catalyst for housing growth. For best value, it should be available as leverage for funding from other sources. Expecting individual participants to be able to stimulate the development of the housing sector, when they are already facing the challenge of adapting to new services and supports in an NDIS environment, is unrealistic.

The NDIS provides an opportunity to address a market failure under the existing disability system. Using funding strategically can generate growth in housing for people with disabilities. The \$550m can be leveraged two to three times - it could also be available to be recycled, as new participants join the Scheme. Growth in affordable and accessible housing is a fundamental building block to addressing the issue of young people being forced into nursing homes.

Unless this funding source can be used to stimulate general and community housing market response, rather than limit its use only within the disability sector, achieving increased integration of housing for people with disability into the community will remain limited.

The major concern arising from the lack of certainty about financial and other incentives to develop new affordable housing opportunities for people with disability, (particularly those who need fully accessible properties such as many of the young people in RAC) is that people will remain stuck in RACs with no new suitable housing for them to move to.

### Social Investment

The work of the Summer Foundation and others has identified that there is an increasing interest in social investment in Australia where investors see a positive social benefit as well as a measure of financial return. This is an option to be explored as a way to partially finance new housing options for people with disability. However, it cannot replace the need for government to provide ongoing funding stimulus for development of housing for people with disability on low incomes.

The Summer Foundation is collaborating with a range of partners to develop a model of social finance that uses government and philanthropic funds to leverage funding from private capital. This will provide insights into the levels of government and/or philanthropic investments that would be required in order for housing projects to be attractive to social investors. The findings of this work will be widely disseminated and a copy will be provided to this Inquiry Committee.

### Shared equity models

With the NDIS more adequately addressing and funding support needs in a more systematic, predictable and long term way for individuals, some families are in a position to contribute some capital towards the cost of providing housing for their family member with disability. This would be one way in which families can provide housing certainty and security into the future for their family member. This model is relevant to young people in RAC. It is also a way of bringing additional capital funding into a system with highly constrained resources. Most families will not be able to fund the full costs of acquiring a home, but some may be able to fund a useful proportion. One of the key challenges will be to identify how the gap between what families can contribute and the full cost of acquisition, can be funded.

Family contribution models appear worthy of further investigation, with policy development work required to ensure efficient, equitable and sustainable models for all parties involved to be developed. Housing Choices Australia has a mixed equity model specifically for people with disability currently in place. This provides a useful initial model for examination as it has been operating since 2003 and now has 50 participants.

<http://www.housingchoices.org.au/pages/mixed-equity-housing.html>

### **Urban planning and housing design**

The knowledge generated through the new types of housing projects described earlier provides insights for how similar projects for people with high and complex disability could be incorporated into new private and community housing development. A planned approach to allocating and designing a small number of units specifically for people with higher and more complex support needs into larger multi unit developments would open up new housing and support opportunities. These projects are best incorporated in well located developments that have a focus on good integration with the local community, access to opportunities for social engagement and ready access to shops, services and facilities <sup>51</sup>.

The lack of accessible and adaptable housing is one of the factors limiting housing options for people with physical disabilities (and many older people as well). If there were more properties designed in accordance with accessible and adaptable design principles through all types of housing stock then there would automatically be more housing choice and opportunities for people with disability including young people in RAC. In addition increased numbers of accessible housing properties would support people with mobility limitations or using wheelchairs being able to visit the homes of family and friends.

To support an increase in accessible and adaptable housing we believe Government should require all new housing to be built with core features that make them accessible and adaptable. These features are outlined in the *Liveable Housing Design Guidelines* <sup>52</sup>.

By adopting the Livable Housing Design Guidelines, dwellings will be:

- Easier to enter
- Safer to move in and around
- More capable of easy and cost-effective adaptation

- Designed to better anticipate and respond to the changing needs and abilities of the people who live in the home.

The targets for accessible design for new housing set out in the *Strategic Plan for the National Dialogue on Universal Housing Design*<sup>53</sup> should be implemented. Progress on achieving the targets has been minimal. Regulation to support the implementation of these targets would assist to increase the supply of accessible housing. This would mean that more accessible and adaptable housing would be available through the general housing market.

The long-term goal of the Summer Foundation is that integrated models of housing will be routinely incorporated into well located new medium and high density housing. In this way we will increase the amount of housing available for people with significant disabilities throughout Australia.

To achieve his vision the Summer Foundation is establishing a project to examine strategies to increase the number of accessible and affordable dwellings for people with disability. We will work to partner with a range of organisations with an aligned interest including the Community Housing Federation of Australia, Liveable Housing Australia, Australian Network for Universal Housing Design, Australian Federation of Disability Organisations, National Disability Services and the National Disability Insurance Agency. As part of this project we will also identify and develop relationships with key stakeholders using the housing demonstration projects to influence the type and percentage of new dwellings designed for people with high and complex disability.

Through this project we also aim to identify levers that could be used by government to increase the supply of affordable housing that is accessible. Once completed the findings of this project will widely disseminated and we will forward a copy to the Inquiry Committee.

### **Implications for Potential Solutions**

- We do not expect many people to move out of RAC as a result of the NDIS due to the lack of housing and support options
- We need a range of options including models that enable people to live with their partner and/or children.
- Continuing to build segregated specialist housing will not develop the range and scale of housing required by young people in RAC.
- The housing needs of people with disability need to be incorporated into mainstream housing strategy.



## 9. Relevant Services

Across Australia, there are current examples of relevant and effective rehabilitation, housing, health service and case coordination options that are assisting to prevent new admissions of young people to RAC. These are the building blocks from which we can create a systematic solution to young people with complex disability being forced into the aged care system. Some of these rehabilitation services are also able to assist people with high and complex needs to transition out of RAC.

### **Slow stream rehabilitation**

Many people at risk of admission to RAC are not eligible for existing rehabilitation services in Australia. Slow stream rehabilitation allows a more extended timeframe to achieve small but functionally significant gains. These services have the potential to significantly reduce the number of admissions of people with severe ABI to RAC by giving people the time and rehabilitation required to maximise their potential so they can return to community living with support.

Some slow stream rehabilitation services are provided in a hospital environment, whilst others are provided in a house (e.g. transitional living service) or the community.

Transitional living services embed rehabilitation into everyday activities in a home-like environment. The aim is to enable people to maximise their independent living skills and abilities, live in the least restrictive environment and, over the longer term, reduce lifetime support needs and cost of care.

### **Caulfield Slow Stream Rehabilitation Service, Victoria**

In October 2014, Caulfield Hospital opened a new Acquired Brain Injury Rehabilitation Centre to provide longer-term slow-stream rehabilitation. The centre delivers extended periods of rehabilitation (3 to 24 months) to people with severe to catastrophic brain injuries with complex care needs that will have lifelong consequences. The centre has a continuum of care, which includes 42 rehabilitation beds, a transitional living service and a community

ABI service. There are three main streams of care for people with complex needs that are unable to be met in other neurological rehabilitation settings:

- People in post traumatic amnesia who require expert care and management
- People with complex medical and behavioural needs with the potential to improve function
- A small number of people in a minimally conscious state who may be admitted for short term care and discharge planning before transfer to a long term housing and support option.

It is anticipated that this new state-wide service will prevent some new admissions of young people to RAC and enable some people to return to live in the community. It will also assist acute hospitals to reduce the number of beds used by patients who are medically stable but have high care and complex care needs that prevent them from returning home.

However, given the difficulty of securing individual support packages (outside NDIS trial sites) or a place in supported accommodation, finding a discharge destination for this group is likely to remain challenging for some time to come.

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**While this service is an important part of the systemic change needed to stop new admissions of young people to RAC, without more accessible and affordable housing options and funding for support, for many people with a catastrophic brain injury the discharge destination is still likely to be RAC.**

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The impact of this new slow stream rehabilitation service will be measured through a \$915,000 research program funded by the Institute for Safety, Compensation and Recovery Research and led by Associate Professor Natasha Lannin from La Trobe University.

*Link to further information: <http://www.alfredhealth.org.au/bettercare/>*

## **Oats Street Brightwater, Western Australia**

Brightwater Oats Street is a 27-place Rehabilitation Facility for people aged 16 and over with an acquired disability and issues related to cognitive impairment. The Oats Street service includes a residential and community based rehabilitation program, a Home and Community Care (HACC) funded Social Support program and a transitional program. The transitional program is specifically for people who have had difficulty finding discharge options from metropolitan hospitals.

At Oats Street, clients develop skills through a consistent process of demonstration, supported engagement and, ultimately, independent initiation and completion. While the rehabilitation and social skills programs aim to maximise functional ability, the transition program also focuses on the identification and development of an appropriate long-term housing and support option. It is expected that clients will participate in the Oats Street program for a period of one to two years with a short end phase of community integration supported by the Oats Street staff.

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**An evaluation that examined the costs and benefits of the Oats Street service found a significant reduction in lifetime care costs of clients following rehabilitation. It is estimated that on average a year of rehabilitation at the Oats Street facility (cost \$321,000) reduces lifetime care cost by \$1.28 million.**

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*Link to further information: <https://www.brightwatergroup.com/ds/oats-street.html>*

## **The Acquired Brain Injury: Slow to Recover Program, Victoria**

The Acquired Brain Injury: Slow to Recover Program (ABI: STR) program was established in 1996 to relocate people with catastrophic brain injury from acute care to RAC or community-based support options. Resources were initially allocated to provide services to at least 100 clients at an average cost of \$50,000 per client per year<sup>54</sup>. The ABI: STR program was developed by DHS in conjunction with professionals in the field of ABI. The program is designed to assist people who have experienced catastrophic brain injury who

are not in receipt of compensation and who require long-term, high-level care. It provides each client with a total package of support that is responsive to their immediate needs and able to be changed over time as they regain function or as they develop new issues (e.g. as a consequence of the aging process). It also supports the families who provide much of the long-term care<sup>55</sup>. This program provides specialist rehabilitation services, case management and brokerage assistance to enable people to purchase a flexible range of supports, irrespective of their living arrangements.

Some young people in RAC receive funding through the ABI: STR program. In June 2000, 33% of people in the ABI: STR program were living in RAC and 67% of this group were under 50 years old<sup>56</sup>. 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<sup>56</sup>. However, the lack of affordable supported housing for people with ABI who have high care needs has been a barrier to returning to community living for many people funded by the ABI: STR program. 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 whose ABI is not related to an acute health episode within the preceding two years are excluded from this program.

The ABI: STR program is unique in Australia. This program actively prevents admissions of some young people with ABI to RAC and provides rehabilitation services to young people with ABI living in RAC<sup>34</sup>. A review in 2008 reported that over the lifetime of the ABI: STR program there had been 234 participants. Of these admissions, 62 people had been discharged from the program, 39 people had died and 133 people remained in the program<sup>57</sup>.

*Link to further information:*

[http://www.monashhealth.org/page/Acquired\\_brain\\_injury\\_slow\\_to\\_recover\\_program](http://www.monashhealth.org/page/Acquired_brain_injury_slow_to_recover_program)

## **Sir William Street Transitional Community Accommodation Service, Victoria**

Sir William Street (SWS) is an innovative model of transitional housing, support and slow stream rehabilitation for people with a primary diagnosis of brain injury and severe cognitive-behavioural impairment. Located in an inner city suburb of Melbourne, with close proximity to shops, transport and services, the model consists of a four-bedroom home with a separate self-contained one-bedroom unit. SWS offers transitional living for up to four people, with one bedroom used for sleep over support staff. A team of therapy assistants staffs SWS. A neuropsychologist and occupational therapist oversee individualised behavioural management plan routines that focus on skill development. Residents are supported to transition to less intensive models of support when they have developed the independent living skills needed to do so. The self-contained unit onsite can be used as a stepping-stone in this process.

SWS has demonstrated a viable housing option, with contextualized slow-stream rehabilitation, for people with the most severe cognitive behavioural impairments who may otherwise have required RAC placement. Research evaluating outcomes of people entering SWS to date has documented positive gains in function, behaviour, community integration and participation of residents over the first two years of operation. Further research is now underway to explore the elements within the built and support environments that may influence outcomes for this complex target group. The outcomes of SWS are being measured through a study led by Libby Callaway from Monash University.

*Link to further information: <http://www.victoriacommunityliving.com.au/>*

## **The Wabu Gadun Bulma Gurrinu Mukanji Centre, QLD**

Synapse, a peak body representing brain injury in Queensland, is working with a consortium to develop a transitional rehabilitation centre in Cairns for indigenous members of the community living with acquired brain injury. The consortium includes non-Government, corporate, Indigenous and non-Indigenous organisations. The \$4.6 million required to build this project is funded by the Federal Government Shared Accommodation Innovation Fund (SAIF) project. The project will be developed on a 7.5 hectare site in Gordanvale. The Wabu Gadun Bulmba Gurriny Mukanji translated from Yidinj means “Come and share the good heart of a healing home”. The centre will provide culturally relevant

independent living options for eight Indigenous Australians living in the Far North. The core initial clients will be selected from a group of long-term patients with ABI at Cairns Base Hospital. One of these patients has lived in the hospital for more than 1200 days. It is anticipated that clients at 'Gurriny' (abbreviated name for project) will stay for two years before either returning to country or moving to another housing and support option in Cairns.

The eight self-contained living units will include spaces that promote external living and include both inside and outside cooking facilities. The indigenous design will promote the seamless integration of indoor and outdoor spaces. A traditional bush food forest and billabong will be used for both nutritional and therapeutic purposes. An elders reference group has provided valuable advice on all aspects of the project from design, model of support and human resource practices. A partnership with James Cook University will provide research that contributes to developing contemporary best practice in disability service delivery.

*Link to further information: [https://synapse.org.au/our-work/aboriginal-torres-strait-islander-support/supported-accommodation-innovation-fund-\(saif\).aspx](https://synapse.org.au/our-work/aboriginal-torres-strait-islander-support/supported-accommodation-innovation-fund-(saif).aspx)*

## **Proactive community health services**

Young people in RAC are often highly susceptible to secondary conditions that can make them critically ill or result in premature death. These secondary medical conditions include pressure areas (31%), contractures (31%), urinary tract infections (23%) and chest infections or pneumonia (18%). Most people have a complex combination of health needs, 88% have three or more health problems<sup>3</sup>.

Periodic admissions to acute health services are common – 42% of young people in RAC are admitted to an acute hospital each year, with some people experiencing multiple admissions. When people with disability with high and complex care needs are admitted to acute hospitals they often require 1:1 support from disability support workers. Given the significant and chronic health needs of many people in this target group, proactive community based health care is necessary and will improve the quality of life and decrease the cost of care of young people in RAC.

## Mobile Assessment and Treatment Service

The Alfred Health Mobile Assessment and Treatment Service (MATS) has proved effective in delivering timely community-based nursing and medical services to support YPIRAC and their networks with the management of secondary health complications. MATS is a mobile medical and nursing service for Hospital Admission Risk Program (HARP) clients which operates seven days per week, with on-call support available 24-hours per day. The aim of the program is to optimise and support primary care management in the community, minimise avoidable emergency department presentations or hospital admissions, and facilitate early discharge from the inpatient setting back to community living.

To be eligible for the service, clients must reside in the Alfred Health catchment in Victoria, have GP support and referral to MATS, with a management plan in place, be a resident of an Aged Care Facility or be an active HARP client. Clients also need to be deemed safe and willing to be treated in the community, acknowledging hospital admission may be necessary. MATS services include in-home assessment and treatment of fever, pneumonia or chest infection, urinary tract infections, fever, hydration and fluid administration, wound care, acute exacerbations of chronic medical conditions (e.g. diabetes, congestive cardiac failure), catheter management and emergency changes, PEG tube and enteral feeding management including replacement of blocked or dislodged tubes, and pain management.

### *Case study*

*Colin sustained an extremely severe acquired brain injury in his early 30s, and entered a RAC facility within the first six months post injury. After more than a decade of living in RAC, Colin was supported by his financial administrator to purchase and move to his own home, with 24-hour in-home support. Colin established a full life in his new home and community, getting a pet dog, going to weekly music and gentle exercise groups at a local community centre, attending Sunday church services, and developing a new social network through these activities. However, Colin experienced ongoing complex care needs, including significant muscle tone changes and dense hemiplegia, the need for a combination of eating and supplementary PEG feeding, and continence and epilepsy management.*

*After a number of years of living in his own home, Colin began to develop episodes of aspiration pneumonia. A speech pathology assessment indicated that Colin's ability to protect his own airway had declined, and he required a comprehensive oral hygiene and suctioning program to attempt to manage the risk of aspiration. The first signs of infection developing were reduced levels of arousal and a low grade fever. With support staff concerned for Colin's welfare at these times, an ambulance was typically called. After his third presentation to the Alfred emergency department in as many months, Colin was referred to the Alfred MATS team.*

*In conjunction with his GP, speech pathologist and physiotherapist, the MATS team established a comprehensive care plan which included a list of symptoms to check for that may indicate an infection and steps for support staff to get prompt primary care assessment (both during business hours and after hours). The proactive care plan meant that Colin received more timely assessment of a possible infection at home and could be prescribed liquid antibiotics administered by PEG. Infections were dealt with promptly and Colin was less likely to use the ambulance services or the hospital emergency department. Where an infection progressed, the MATS team was available to liaise with Colin's medical team and implement IV antibiotics and supplemental oxygen, and support a respiratory management plan at home. On some occasions hospitalisation was required, but more often Colin could be supported by the MATS team and remain at home.*

*Over time, in order to manage ongoing aspiration, Colin's nutritional intake was delivered completely by PEG tube, and the MATS team were involved in training new support staff on Colin's comprehensive care and enteral feeding plan. The MATS team also worked with Colin's family and support team to undertake and document advanced care planning for future medical intervention.*

*Colin's quality of life, and access to proactive healthcare, was*

*significantly improved by the services received through the Alfred MATS team. The program reduced the cost of Colin's care, both directly through reduced ambulance and hospital service utilization, as well as indirectly as his health was maintained at a higher level and he needed less restorative rehabilitation post infection (e.g. chest physiotherapy). Direct support staff and family received the training they required to provide the daily support Colin required relating to secondary complications and a clear advanced care plan was in place.*

*Link to further information:*

<http://www.alfredhealth.org.au/Page.aspx?ID=453>

## **Case co-ordination**

Given their level of disability and complex needs, many people in this target group need proactive case co-ordination services to respond to their changing needs.

## **ABI Case Management Service**

Acquired Brain Injury (ABI) Case Management Services was set up to support people for a time-limited period after brain injury. The program recognises the specific skills and knowledge required to address areas of need such as neurological rehabilitation, cognitive and behaviour support, housing and re-gaining identity after injury. Historically disability case management utilises a developmental framework to maximise potential for engagement, but this approach is usually inappropriate for those acquiring disability later in their lives.

ABI Case managers support people in accessing specialist neurological as well as general disability and mainstream services, and in developing skills to participate in the community as fully as possible.

For those with complex and catastrophic ABI, the pathway to recovery frequently takes many years, and often involves a complex range of allied health, medical and psychological interventions, along with support for family members whose lives and life-roles are often disrupted or changed permanently. ABI case managers set up individualised rehabilitation and support programs that can work in the aged care system. They also support transition back to family living with additional services, or into appropriate supported community housing when opportunities become available.

For further information: <http://www.melbournecitymission.org.au/services/disability-services/living-with-an-abi/program-detail/abi-case-management>,  
[http://www.monashhealth.org/page/Acquired\\_brain\\_injury\\_slow\\_to\\_recover\\_program](http://www.monashhealth.org/page/Acquired_brain_injury_slow_to_recover_program)

### **The Continuous Care Pilot**

The Continuous Care Pilot aimed to identify better options to support younger people with neurological conditions and avoid admission into RAC. There were 19 participants under 50 years of age in the program who had a diagnosis of a progressive neurological condition (such as Spino-Cerebellar Ataxia, Cerebral Palsy/Cervical Dystonia, and Multiple Sclerosis) and who lived in Victoria <sup>58</sup>.

The program had six steps: transition to the program, specialist health and social assessment, information sharing and knowledge transfer, decision making and implementation of plans, planning to meet contingencies (including the provision of brokerage funds); and monitoring and review.

The step covering transition to the program involved:

- Defining 'criteria' for different diagnostic groups to identify the point at which a person with a chronic neurological condition should be offered a continuous care program
- Identifying 'red flags' for this 'at risk' group and educate health and community providers to recognise risks
- Informing public and consumers (including consumer groups).

An evaluation found that the program almost certainly prevented between two and five admissions to RAC during its period of operation. It also achieved other substantial benefits for a number of participants including resolving problems with service providers, accessing additional or more appropriate services, accessing larger and more adequate funding packages, identifying and resolving outstanding equipment issues and establishing more acceptable respite arrangements <sup>58</sup>.

For further information: <http://www.ypinh.org.au/images/stories/pdf/ccp-rep-final082010.pdf>

### **Implications for Potential Solutions**

- There are a range of services throughout Australia that provide the building blocks of the system required to solve the issue of young people in nursing homes.
- These services need to be replicated so that they readily available in every jurisdiction as part of a co-ordinated system.



## 10. What are the potential solutions?

People under 65 years of age living in RAC are eligible for funding through the NDIS. The NDIS will provide the funding for support and equipment that young people in RAC (or at risk of entry) need to live in the community. However, the NDIS cannot stop the flow of young people into RAC on its own<sup>3</sup> or facilitate their move out of RAC. We also need to change the system to be more proactive in preventing new admissions, and more accessible and affordable housing needs to be built.

There are five key issues that need to be addressed to resolve the issue of young people in RAC in Australia:

1. Ensure that young people in RAC get access to the NDIS
2. Build the capacity of young people in RAC
3. Prevent new admissions
4. Increase the range and scale of housing
5. Cross-sector collaboration

### **1. Ensure that young people in RAC get access to the NDIS**

In 2014, 58 young people living in RAC were supported through the Summer Foundation *NDIS Connections* project in the Barwon and Hunter NDIS trial sites. So far this project has found and informed all 58 about the NDIS, supported 29 to register, supported 27 people to plan and 24 people to implement their plan. Through these projects we have found that 58% of young people in RAC were not registered with the NDIA.

The work required to support this group to participate in the NDIS is time and resource intensive. The person with disability often has a limited ability to provide consent or participate in decision-making due to their cognitive and communication difficulties. The person's family and social networks are often either complex or virtually non-existent. Some (18%) don't have either a family member or anyone to advocate for them.

The NDIA systems and processes seem to assume that participants either have the cognitive capacity to complete forms or alternatively have access to a family member or a formally appointed guardian who is able to complete paperwork on their behalf – this is often not the case for the marginalised population of young people in RAC. In the Hunter NDIS trial sites matching a young person in RAC with suitable housing and support options is further complicated by limitations on the number of “new participants” phased into the NDIS each quarter <sup>59</sup>.

On average it has cost \$3900 for the Summer Foundation to find each younger person in RAC and support them (and their families) to register, prepare for the planning process, undertake planning and implement their NDIS plan. This includes time to establish productive relationships and develop networks to find people in each trial site. While there is scope to work with NDIA to make the registration process more efficient, it is also likely that the first people we are engaging are people that are the least marginalised and complex of the young people in RAC population.

It is imperative that we continue to build the understanding of what is required to ensure equitable access to the NDIS and equitable outcomes for young people in RAC. Therefore the Summer Foundation is currently seeking further philanthropic funding to partner with other not-for-profits and extend the *NDIS Connections* project to trial sites in Western Australia and the ACT. We aim to reach all 321 people under 65 in the NDIS trial sites by July 2016.

Given that young people in RAC have high and complex needs, ensuring that they are included in the NDIS trial sites and national roll out may have a significant impact on NDIS liabilities. However, the Productivity Commission specifically identified this target group, and supporting young people in RAC to tell their stories about the difference the NDIS has made will also assist to generate public support for the NDIS.

### **Potential Solutions**

- Use action research to develop an evidence base regarding barriers to participation
- Collaborate with the NDIA to increase the efficiency of the registration and planning process for young people in RAC

- Streamline NDIS eligibility, and eliminate the need to prove eligibility for people under 65 with obvious disability living in RAC
- Build the understanding and capacity of NDIA Local Area Co-ordinators (LAC) in each trial site to work with the aged care system and young people in RAC
- NDIA to access Commonwealth aged care facility data to locate everyone under 65 living in RAC in trial sites – LACs and Summer Foundation to coordinate visiting, engaging and supporting participation in the NDIS.
- The Summer Foundation and the NDIA to collaborate to develop a strategy to scale this ‘case finding’ work nationally from 321 people in June 2016 to 3000 by 2019.
- NDIA to give young people in RAC with potential alternative housing options high priority where there are limits on the number of “new participants” being phased into the Hunter trial site.
- NDIA to fund one-off “access packages” for organisations to find and support those young people living in RAC to register with NDIA, build their capacity to prepare for the planning process, and support planning and the implementation of an initial NDIS plan.

## **2. Build the capacity of young people in RAC**

Most (56%) people under 65 living in RAC are not receiving any disability support services and are lonely, bored and effectively excluded from society. Capacity to engage in goal setting and planning is often hampered by limited knowledge of the possibilities for life beyond RAC. If young people in nursing homes are to benefit from the opportunities available through the NDIA they require support to build their capacity to be actively involved in planning their future, setting goals, planning and choosing appropriate services and supports.

The Summer Foundation has produced three videos that document the experience and outcomes of young people in RAC in the NDIS trial sites. These videos were funded by philanthropic grants from the Geelong Community Foundation. Each of these videos cost approximately \$5000 to produce.

**Kirrily Hayward** [video link](#)

Kirrily lives in RAC in Geelong and wants to move out into shared supported accommodation. She is sorting out her NDIS package and struggling to find a suitable housing alternative.

**Russell and Evelyn Bramley** [video link](#)

Russell is married to Evelyn. Evelyn has recently been able to move out of RAC due to NDIS funding. Russell speaks about the importance of having Evelyn home, back as part of the family.

**Vanda Fear** [video link](#)

Vanda is the mother of Paul. Paul was at risk of admission to RAC. His family took him home despite recommendations from health care professionals. Paul was able to access an individualised disability funding package, and has recently made the transition to NDIS. Vanda has some valuable insights into the planning process and gaps in providing for someone with complex health needs at home through the NDIS.

While these videos are useful resources to assist young people in RAC and their families to prepare for the NDIS, a wider range of stories and resources are needed.

As many as 5700 young people in RAC in Australia will not be eligible for funding from the NDIS until 2019. Our experience over the past year in supporting young people in RAC with information and assistance to navigate the health, disability, aged care and housing service systems indicates that outside the NDIS trial sites it is harder than it has been for many years to secure funding from state disability services. Outside the NDIS launch sites, without access to timely disability supports nearly 1300 people under 60 will continue to be admitted each year in Australia. Nearly 300 of these people are expected to be under 50 years of age. They will lose skills, abilities and social connections and some of them will develop secondary health conditions without access to therapy or customised seating or other essential equipment.

## Potential Solutions

### Resources

Resources are needed to build the capacity of young people in RAC and their families. For example:

1. Short videos that document the experience and outcomes of a range of young people in RAC in the NDIS trial sites and their families.
2. Multi-media online resources to capture the actual pre-planning and planning process by 2-3 people that provide examples of how to actively participate in the planning process.

### Outside the NDIS trial sites

1. Ensure young people in RAC outside NDIS trial sites are connected to an advocacy organisation that provides regular information regarding the progress, roll-out and outcomes of the NDIS for YPIRAC
2. Advocacy organisations to contact young people in RAC and their families prior to NDIS rolling out in their region in order to inform, build their capacity and support them through the registration and planning process.

## 3. Prevent new admissions

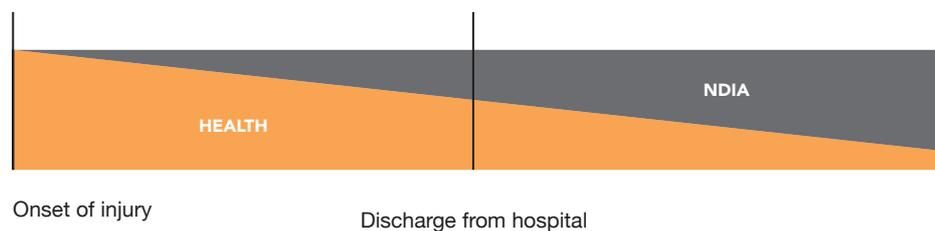
Once in RAC, young people lose skills and their social networks diminish. Preventing new admissions is a more efficient use of resources than waiting for people to be admitted to RAC and then moving them out. Most (59%) young people are admitted to an acute or rehabilitation hospital before their first admission to RAC.

The YPIRAC initiative (2006-11) achieved some significant goals, but did not create the systemic change required to stem the flow of young people into RAC:

- From 1999-2012 there was an overall downward trend in the number of people under 50 admitted to RAC each year.
- From 2011-12 to 2012-13 the number of people under 50 admitted to RAC increased from 180 to 292.
- From 1999-2013 there was an overall trend with an increase in the number of people aged 50-59 admitted to RAC each year.

As a shift in focus occurs from recovery and rehabilitation to lifetime care and support, there will also be an overall shift of responsibility from health services to the NDIA. Over time the NDIA will need to take on more responsibility for NDIA participants. However, health services are likely to be involved intermittently and over the long term to proactively manage secondary health conditions and provide timely rehabilitation interventions.

**Figure 10.1: Proactive model for people with catastrophic acquired brain injury**



## Potential Solutions

1. Workshops involving health (acute and rehabilitation), Aged Care Assessment Teams, NDIA and disability and housing providers in the NDIS trial sites to understand and address challenges and barriers to returning people with high and complex support needs to community living, and to clarify and identify common goals, and develop outcome measures and potential solutions.
2. NDIA to fund hospital liaison roles that work within the health system and are actively involved in exploring discharge options and coordinating supports, home modifications and equipment as early as possible in the hospital stay.
3. Slow stream rehabilitation and transitional services are needed in every state and territory to give people with severe brain injuries who no longer require acute hospitalisation the time they need to demonstrate their potential before they are forced into RAC.
4. Proactive case co-ordination services are required to respond to the changing needs of people with degenerative conditions such as multiple sclerosis, motor neurone disease and Huntington's disease.
5. Health outreach services that combine direct care with a 24-hour on-call service are required for people in the target group who require intermittent nursing care. These

services work with the individual, their support network and doctors to develop action plans to monitor and address predictable medical conditions (e.g. recurrent urinary tract or chest infections, epilepsy and pressure areas). These plans would enable support staff to proactively identify early warning signs and initiate appropriate intervention. Proactive health planning will reduce the incidence of secondary complications and acute hospital admissions <sup>3</sup>.

6. A pilot program jointly supported by Health and NDIA based on the [Alfred Mobile Assessment and Treatment Service \(MATS\)](#) program, would provide an evidence base for a model of community based health support for people with disability with high and complex needs, to be rolled out across Australia. This pilot is likely to demonstrate cost efficiencies for both Health and NDIA.

#### **4. Increase the range and scale of housing**

The introduction by the Australian Government of the NDIS provides a new context and greater urgency for addressing housing needs of people with disability. The NDIS aims to address the problems of an inadequate and inequitable disability system identified in the Productivity Commission's report <sup>24</sup>.

However, the positive impact of the NDIS will remain limited if there is no significant increase in the availability of affordable and accessible housing across all communities. The lack of affordable and appropriate housing options remains a major obstacle to people with disability being able to maximise their independence and have greater choice and control over their lives, even with the additional resources available through the NDIS.

It is clear that the NDIS cannot alone achieve the housing outcomes needed for people with disability. Unless the whole community begins to act now, the lives of many people with disability and their families will not be improved, and the anticipated social and economic benefits to the wider community from the NDIS will be limited. Filling this gap on a sustainable basis will require housing for people with disability to be seen as a mainstream housing issue. Addressing the housing needs of people with disability should form a part of any affordable housing strategy.

## **Potential Solutions**

1. Continue to develop demonstration projects and evaluate them against the high level goals of the NDIS, to ensure effective and cost –efficient outcomes are achieved over a lifetime
2. A Housing policy for people with disability to be developed within the context of mainstream housing, to reinforce social inclusion
3. NDIA to establish the fund for user cost of capital as a lever across the varied aspects of the building industry, to expand the supply of affordable and accessible housing  
Planning policy and regulations that require adequate numbers of housing units that meet Livable Housing design standards to meet demand, are incorporated into all new urban in-fill and greenfield sites

## **5. Cross-sector Collaboration**

Solving the issue of young people in RAC on a sustainable basis requires strong government policy leadership and effective collaboration across many sectors. No one sector has the expertise or resources to prevent new admissions of young people to RAC or to develop the range and scale of housing, rehabilitation and ongoing support required for this target group. The complex needs of young people in RAC requires a more coordinated approach that involves health, housing and aged care rather than just looking to disability services to solve the issue alone as has happened in the past.

## **Potential Solutions**

1. The NDIS provides the best opportunity in a generation to address the unmet demand for services and supports to people with a disability, but it cannot do it alone. Collaborative approaches with the Housing, Health and Aged Care sectors in particular need to be in place to provide alternative opportunities to young people who are in nursing homes;
2. There are a number of important initiatives already in place across Australia that show how collaboration and cooperation between sectors have made significant improvements in the lives of young people with complex disability – these need to be built upon and incorporated into the roll-out of the NDIS across Australia.

3. It is a clear need to ensure that acute health and rehabilitation services continue to provide quality care for people with disability. For those with acquired brain injury and neurological disease, the NDIS needs to adopt a rehabilitative framework in planning its disability response, and ensure that expected health needs over a lifetime are not reduced to a referral system for acute medical interventions. More integration of health and disability services is required across both policy and practice to reduce risk and achieve efficiency.
4. Complexity across the disability, health, housing and aged care service systems means that people with disability are often unable to find a way through the maze of options available to them. Hospital liaison, case management and case coordination services all provide versions of a single point of reference that assist people to find their best options to improve their lives. For young people in nursing homes, this service type should be readily available, as it will be the exception where it is not needed.





## 11. Conclusion

It has been 10 years since the initial Senate Inquiry that brought the issue of young people in RAC to the attention of our government. The report from the Senate Inquiry into Aged Care, released in June 2005, along with the transcripts and submissions, provided a rich array of anecdotal evidence about the social exclusion of young people in RAC<sup>16</sup>. In response to the concerns raised in this report, a new national initiative was agreed upon by COAG in February 2006.

In 2006, Governments jointly established and funded the \$244 million national five-year Younger People in Residential Aged Care (YPIRAC) program. The program was implemented through disability services departments within each state and territory government. As a result of this program, 250 young people were able to move out of nursing homes and a further 244 young people avoided being admitted. Throughout Australia, 65 new services were created to provide housing and support for over 322 people. Summer Foundation research found that moving out of nursing homes enriched the lives of young people with disability. They went outside more often, had more opportunities to make everyday choices and spent fewer hours in bed.

One of the key findings from the YPIRAC initiative is the importance of preventing new admissions to aged care facilities. It is a much better use of resources to stop people from entering than letting them enter and then trying to move them out. Once in a nursing home, young people lose skills and their social networks diminish. Most (59%) young people are admitted to an acute or rehabilitation hospital before their first admission to residential aged care (RAC). This suggests that disability services need to partner with health services to develop pathways from hospitals to community living in order to prevent new admissions. The YPIRAC initiative made a significant difference to the lives of the people who received services but it did not create the systemic change needed to stem the flow of young people into nursing homes. Since the YPIRAC initiative ended, the system has largely reverted to the way things were in the past. The new housing and support options developed for this target group are full and vacancies are usually only created when a resident dies. Over 300 people under 50 are still admitted to nursing homes each year in Australia.

The disability sector is currently being transformed with the introduction of the National Disability Insurance Scheme (NDIS). People under 65 years of age living in RAC are eligible for funding through the NDIS. The NDIS is one part of the solution to the issue of young people being placed in nursing homes. The NDIS will provide the crucial funding for support that young people in aged care or at risk of entry need to live in the community.

Based on current research and experience with previous government programs, most young people in nursing homes will miss out on the NDIS. They are unable to initiate and complete the registration process due to their cognitive and communication difficulties. They often have no one to advocate on their behalf. There needs to be a national strategy to ensure that the most vulnerable and disadvantaged people with disability get equitable access to services funded through the NDIS.

The NDIS cannot on its own stop the inappropriate placement of young people in RAC. We need to change the system to prevent new admissions. More accessible and affordable housing also needs to be built.

The NDIS has limited funding for capital to support the development of new housing for young people in nursing homes. Due to the current overall shortage of accessible and affordable housing we do not expect many young people to move out of aged care facilities as a result of the NDIS. A range of housing options including options for people to live with their partner and/or children is needed. Australia desperately needs a long-term strategy to create more housing that is both accessible and affordable. Rather than continuing to build segregated specialist housing, the housing needs of people with disability need to be incorporated into mainstream housing strategy.

Solving the issue of young people in RAC on a sustainable basis requires strong government policy leadership and effective collaboration across many sectors. No one sector has the expertise or resources to prevent new admissions of young people to RAC or to develop the range and scale of housing, rehabilitation and ongoing support required for this target group. The complex needs of young people in RAC requires a coordinated approach that involves health, housing and aged care rather than just looking to disability services to solve the issue alone as has happened in the past.

## Appendix A

### Young People in RAC In NDIS trial sites

Permanent residents as at 30 June 2013

Local Government Area			
Barwon Region (Vic)	Under 50	50-64	Under 65
Colac-Otway (S)	0	7	7
Greater Geelong (C)	7	66	73
Surf Coast (S)	0	2	2
Queenscliff (B)	0	0	0
<b>Total</b>	<b>7</b>	<b>75</b>	<b>82</b>
Hunter Region (NSW)			
Lake Macquarie (C)	7	48	55
Maitland (C)	0	6	6
Newcastle (C)	19	69	88
<b>Total</b>	<b>26</b>	<b>123</b>	<b>149</b>
Perth Hills (WA)			
Kalamunda (S)	0	11	11
Mundaring (S)	0	5	5
Swan (C)	0	8	8
<b>Total</b>	<b>0</b>	<b>24</b>	<b>24</b>
ACT			
ACT	2	64	66
<b>Total</b>	<b>2</b>	<b>64</b>	<b>66</b>
<b>Total in NDIS trial sites</b>	<b>35</b>	<b>286</b>	<b>321</b>
<b>Total across Australia</b>	<b>605</b>	<b>5604</b>	<b>6209</b>

## New admissions 1 July 2012 – 30 June 2013

### Local Government Area

<b>Barwon Region (Vic)</b>	<b>Under 50</b>	<b>50-64</b>	<b>Under 65</b>
Colac-Otway (S)	1	4	5
Greater Geelong (C)	3	27	30
Surf Coast (S)	0	0	0
Queenscliff (B)	0	0	0
<b>Total</b>	<b>4</b>	<b>31</b>	<b>35</b>
<b>Hunter Region (NSW)</b>			
Lake Macquarie (C)	6	28	34
Maitland (C)	0	2	2
Newcastle (C)	5	31	36
<b>Total</b>	<b>11</b>	<b>61</b>	<b>72</b>
<b>Perth Hills (WA)</b>			
Kalamunda (S)	2	4	6
Mundaring (S)	0	3	3
Swan (C)	1	0	1
<b>Total</b>	<b>3</b>	<b>7</b>	<b>10</b>
<b>ACT</b>			
ACT	0	23	23
<b>Total</b>	<b>0</b>	<b>23</b>	<b>23</b>
<b>Total in NDIS trial sites</b>	<b>18</b>	<b>122</b>	<b>140</b>
<b>Total across Australia</b>	<b>292</b>	<b>2400</b>	<b>2692</b>

Note: Clients with a transfer in the year are not counted. The NDIS trial sites in South Australia, Tasmania and the Northern Territory are not included in the table above because there were no young people in RAC eligible for the NDIS in these trial sites. The NDIS trial site in Tasmania focuses on people aged 15 to 24 years, South Australia focuses on children aged 0-14 years and there are very few aged care facilities in the Barkly (NT) trial site. Source: AIHW 2014

## Appendix B

### Participants in NDIS Connections Project

November 2014

	Victorian NDIS trial site	NSW NDIS trial site	Both NDIS trial sites
Number of participants	21 people	29 people	50 people
<b>Age (M, R) years</b>	M=52.9yrs, R=28-64yrs	M=53.7yrs, R=29-64yrs	M=53.3yrs, R=28-64yrs
Sex (%)			
Male	23.8%	58.6%	41.2%
Female	76.2%	41.4%	58.8%
Disability type (%)			
Acquired Brain Injury	47.6%	62.2%	54.9%
Mental health issue	19%	3.4%	11.2%
Multiple Sclerosis	14.2%	3.4%	8.8%
Huntington's Disease	-	6.9%	3.4%
Intellectual disability	4.8%	6.9%	5.8%
Spinal cord injury	-	3.4%	1.8%
Spina Bifida	4.8%	-	2.4%
Parkinson's Disease	4.8%	-	2.4%
Other	4.8%	-	2.4%
Not known	-	13.8%	6.9%
Has family/advocate available (%)			
Yes	81.0%	72.4%	76.7%
No	19.0%	17.2%	18.1%
Not known	-	10.4%	5.2%
Already known to Disability Services (%)			
Yes	23.8%	20.7%	22.2%
No	42.9%	69.0%	56.0%
Not known	33.3%	10.3%	21.8%
Already known to Disability Services (%)			
Yes	23.8%	20.7%	22.2%

No	42.9%	69.0%	56.0%
Not known	33.3%	10.3%	21.8%

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Already registered for NDIS (%)

Yes	52.4%	31.0%	41.7%
No	47.6%	69.0%	58.3%

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Receiving YPIRAC-funded services

Yes	4.8%	24.1%	16.9%
No	71.4%	72.4%	71.9%
Not known	23.8%	3.4%	13.6%

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