

2015



Youngcare Ltd

SENATE INQUIRY SUBMISSION

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



Executive Summary

The problem of young people residing in residential aged care (RAC) requires a whole of community approach from both government and non-government organisations. It is a problem that is felt equally throughout Australia, but disproportionately by young people with high care needs and their carers who represent some of the most marginalised members of our society. The issue of young people in RAC is a problem not only because it creates social isolation, financial hardship and inequity but also because RAC is unable to appropriately cater for the needs of a person in their younger years, and can contribute to creating secondary illnesses which inhibits further rehabilitation.

Disunity between state and territory disability and health government departments, and the federally run aged care system are contributing factors to how this problem became so pervasive. Full implementation of the National Disability Insurance Scheme (NDIS) offers potential progress on this matter, but will not provide a complete solution. While the reasons young people are placed in aged care varies, so too does the way in which we can assist them to exit the aged care system.

Youngcare's 10 years of dedication to solving this crisis has produced a collection of data and information that can elaborate on efficient ways to divert premature entry into aged care through micro grants, and offer insight to the process of assisting people to transition from aged care into more suitable housing options. Youngcare's partnership with Griffith University has also produced an evidence-based model of care and best practice in building accommodation facilities that cater to the needs of people with profound and severe disabilities.

This submission outlines Youngcare's experiences in working to address and resolve the crisis of young people living in RAC. The submission also proposes several recommendations that are of relevance to young people in RAC and the ongoing implementation of the NDIS in Australia. Finally, recommendations concerning immediate changes that are required to lessen the degree of disadvantage that young people in RAC presently face, or long term changes such as enhanced collaboration across government, non-government, corporate and philanthropic sectors delivering innovative housing and care solutions are outlined.

Recommendations

- Specific targeted programs to ensure young people residing in aged care are located, informed and supported to access the NDIS.
- The provision of immediate and thorough assessment of individual needs regarding service, rehabilitation and recovery pathways.
- Under the NDIS there be provision for a continuum of care with the ultimate aim of transitioning people with high care needs to age appropriate housing of their choice and under their control.
- Allow young people in aged care to access state and territory aids and equipment schemes.
- Provide appropriate prescribed specialist services to young people in aged care such as: speech, physiotherapy, occupational therapy and other allied health services.

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- Remove the requirement of bonded fees for young people with high care needs in residential aged care.
 - That a federal government funded disability housing innovation program be established that would call for projects from the private and the not-for-profit sector to provide accommodation solutions for young people with high care needs per the example of the Queensland State Government's Elderly Parent Carer Innovation Trial (EPCIT) program.
 - Capital from these sectors initial funding could be leveraged and provide appropriate housing options for the young people currently living in RAC or at risk of living in RAC, that better reflect the choice in accommodation, available accommodation available in the general population. Such initiatives will stimulate the development of more evidence-based quality housing outcomes and will stand as viable, replicable models to be adopted by the housing, construction and disability support sectors as well as mainstream housing developers, for growth in appropriate choices and volumes of accessible housing stock.
 - Building regulations be changed to ensure there is consistency across Australia. Regulations should also stipulate that all new buildings must comply with simple design innovation to enable easy conversation of all new homes such as increasing the minimum width; that will include increase minimum width of doorways to accommodate the access wheelchairs and aging in place.



Glossary of Terms

ABI	Acquired Brain Injury
ACAT	Aged Care Assessment Team
ADHC	Aging Disability And Home Care
AHCG	At Home Care Grant
CP	Cerebral Palsy
DHS	Department of Human Services
DS	Disability Services
EPCIT	Elderly Parent Carer Innovation Trial
HACC	Home and Community Care
HS	Home Soon
MN	Motor Neuron Disease
MS	Multiple Sclerosis
NDIS	National Disability Insurance Scheme
NGO	Non-Government Organisation
PWD	People with Disability
RAC	Residential Aged Care
YCC	Youngcare Connect
YPIRAC	Young People in Residential Aged Care



Contents

Executive Summary	1
Glossary of Terms	3
1.0 Introduction.....	5
2.0 About Youngcare	5
3.0 Young People in Residential Aged Care.....	5
3.1 Recommendations	8
4.0 How Do Young People Come To Live In RAC?	8
5.0 Inappropriateness of Young People in Aged Care.....	9
5.1 Social Isolation.....	10
5.2 Financial Burden.....	10
5.3 Inadequacy of Services	11
6.0 YPIRAC Scheme	13
7.0 At Home Care Grants.....	14
8.0 Home Soon grants	16
8.1 Lessons Learnt	16
8.1.1 Combined Effort	16
9.0 Disparity of Aids and Equipment Programs between States and Territories.....	17
10.0 Partnership with Griffith University	18
11.0 Testimony - Todd.....	18
12.0 Solutions.....	20
12.1 Short Term Solutions.....	20
12.2 Recommendations	22
13.0 Access to Young People in RAC	22
13.1 Housing.....	22
13.1.1 Youngcare Housing Solutions.....	23
13.2 Addressing Funding Misalignment.....	Error! Bookmark not defined.
13.3 Community and Corporate Appeal	25
13.4 Recommendations	25
13.5 Discord between State and Federal Government Services.....	25
14.0 Contact Details	27
References.....	28



1.0 Introduction

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

Youngcare believes that younger people with disability should not be admitted to residential aged care (RAC) facilities and that younger people currently living in RAC facilities should be relocated to community-based accommodation with appropriate supports.

Youngcare believes that RAC is not appropriate for young people. Combating this problem requires effort from government together with the broader community and is an issue that can be solved.

Youngcare greatly values the opportunity to share the experiences and learnings across the last 10 years since the organisation was established, and to outline work currently being undertaken as part of the 'whole of community' approach necessary to provide an enduring solution to this issue.

2.0 About Youngcare

Youngcare is a nationally registered charity and not for profit organisation formed in 2005 to help young Australians with high care needs for whom living in, or facing a threat of living in aged care, is very real.

Youngcare aims to help young people avoid admissions to aged care and to develop viable and replicable models to solve this problem once and for all, and to give young people with high care needs the choice in housing and accommodation they deserve. Youngcare envisages a future that sees every young Australian between 18 and 65 years with high care needs living in age appropriate accommodation leading the young life they deserve.

Youngcare is funded through corporate sponsorship and fundraising activities. Along with building accommodation for young people with high care needs and providing a national information and support phone service, Youngcare also offers micro grants (At Home Care Grants) to people in New South Wales, Queensland, Victoria and for the first time in 2015, Tasmania and the Australian Capital Territory. In 2014 Youngcare piloted a Home Soon grants program in Queensland to help young people transition out of RAC and back into their community.

3.0 Young People in Residential Aged Care

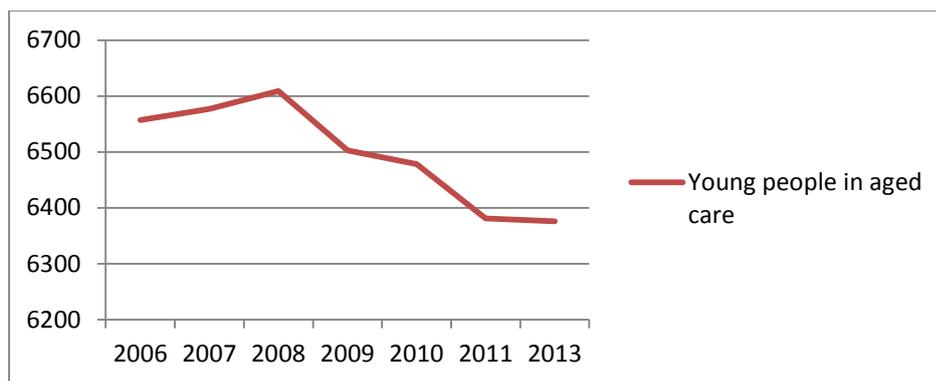
RAC is not designed to provide an individualised and lifetime approach support for young people, but rather to support the declining health needs of people aged over 65 years. In addition, aged care does not provide resources to support the wide ranging and fluctuating health needs of young people with complex conditions, yet alone develop their wellbeing and life aspirations. Aged care also does not respond well to sudden or adult onset conditions.

While the distribution of younger people in RAC in Australia is predominately higher in the most heavily populated states, the problem is pervasive throughout the nation. Young people in RAC

comprise between 0.01 % and 0.03% of individual state and territory populations, with South Australian accounting for the highest proportion of this statistic and the ACT the lowest¹.

Precise figures of exactly how many people under 65 are in RAC are not currently known. The most recent survey was undertaken in 2013², and while a slight fall in figures over the past three years can be seen (refer Figure 1), there is no publicly available data on the current status of this situation. Government initiatives like the Young People In Residential Aged Care (YIPRAC) scheme have been instrumental in assisting people to find more age-appropriate forms of accommodation, however we are unaware of how endemic the problem remains. While figures were compiled during the YIPRAC initiative until 2011 and showed promising improvement, a survey in 2013 by the Australian Institute for Health and Welfare showed these figures had plateaued (refer Figure 1). Adequately addressing this problem requires comprehensive understanding of how pervasive it is, however the lack of current statistical data presents a logistical road block to this as well as to resolution. As shown in Figure 2, previous data suggests that the amount of younger people in RAC fluctuates, and that the recent drop in placements may not be an indication of permanent change.

Figure 1 Young people in aged care- the most recent data collection 2006- 2011³ ⁴



**Data taken from two separate sources (2006 – 2011) and (2013 separately)*

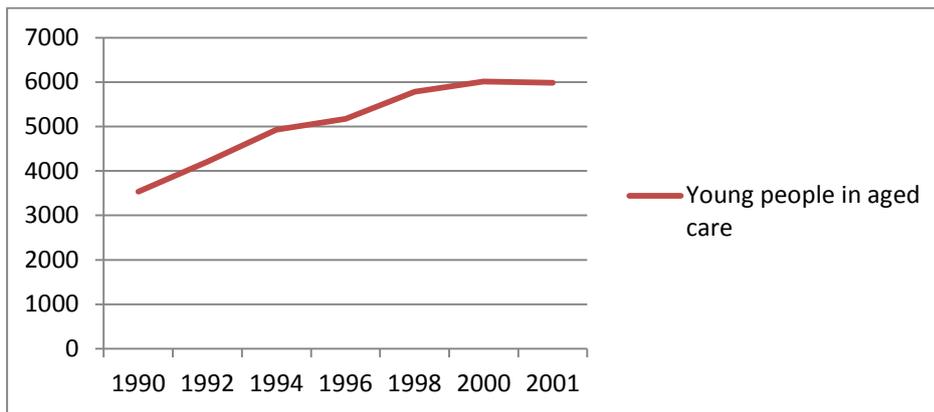
¹ <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=10737421563>

² <http://www.aihw.gov.au/aged-care/residential-and-community-2012-13/characteristics-of-clients/>

³ <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=10737421563>

⁴ <http://www.aihw.gov.au/aged-care/residential-and-community-2012-13/characteristics-of-clients/>

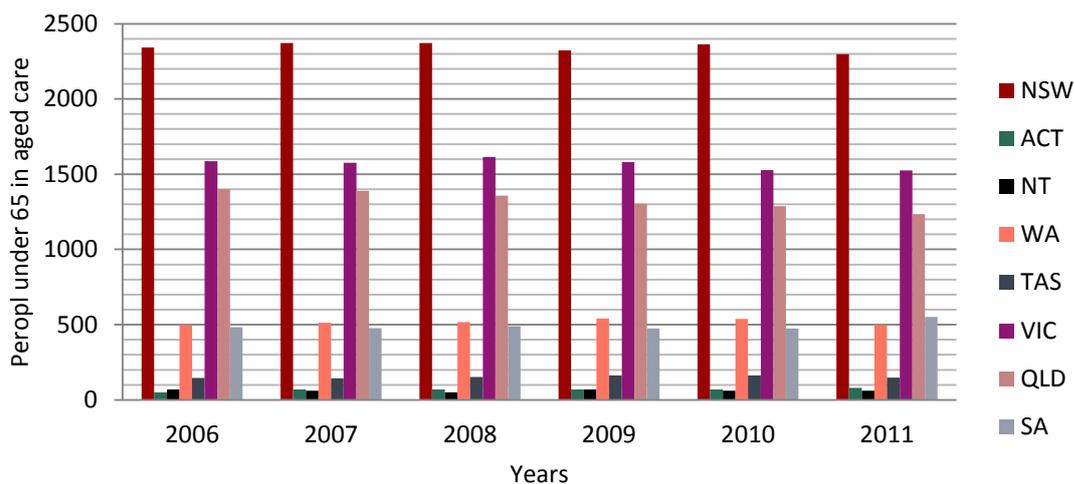
Figure 2 Young people in aged care - previous data 1990- 2001⁵



The threat of new admissions for young people with disabilities into RAC continues to exist among all states and territories because too little is being done to address the root causes of this endemic issue. For young people who still face the risk of leaving the family home to enter RAC, their accommodation and care is typically owed to unpaid care givers (i.e. informal care from immediate family) who look after their daily needs at the expense of leaving the paid workforce. This places enormous financial and emotional pressure on families who are already coping with their loved one’s situation.

In addition, families of young people in RAC can be forced to face a tremendous financial burden of paying for the care of their loved ones because they fall outside of the state or territory funded disability services. Real financial crisis often occurs and families are forced to draw on or sell assets to pay for daily care that should be available. This is a very real gap in the system that penalises the young person and their families. Section 5.2 provides further details on this matter.

Figure 3 Young people in RAC by year and state over five year period⁶



⁵ http://www.ncoss.org.au/bookshelf/disability/submissions/0209_yp_dis_nh_dp.pdf

⁶ <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=10737421563>

3.1 Recommendations

- Specific targeted programs to ensure young people residing in aged care are located, informed and supported to access the NDIS.
- The provision of immediate and thorough assessment of individual needs regarding service, rehabilitation and recovery pathways.
- Under the NDIS, there be provision for a continuum of care with the ultimate aim of transitioning people with high care needs to age appropriate housing of their choice and under their control.

4.0 How Do Young People Come To Live In RAC?

People under 65 with a disability enter RAC for a variety of reasons, but predominantly due to a lack of state-funded disability services and a shortage of suitable housing. In addition, a lack of information on available services also plays a significant role in the placement of young people in RAC. Many people under 65 entering RAC do so after a long hospital stay following an accident or later on set illness⁷. In such situations, families are often unfamiliar and unsure how to access disability services, and left only with the assistance of hospital social workers to find the help they need after discharge.

Hospitals operate to provide acute care services and patients no longer needing acute medical care end up using the limited resources hospitals have available. When a person is assessed in hospital as needing a high level of care upon discharge that cannot be provided at home, hospitals are left in the unfortunate position of having to put pressure on families to find alternative accommodation. The list below provides some insight into the process that can occur when assessing the needs of a person in hospital:

- Hospital staff will support family to access assessment from disability services
- Disability services will assess and identify eligibility
- Disability services very often have no capacity to provide necessary care and will inform the hospital and family of this
- Hospital services will access the aged care assessment teams to provide and assessment
- ACAT will then seek approval from the state disability services (Under a *Memorandum of Understanding*) to provide an aged care assessment
- Assessment carrying out by ACAT
- If services is required by the individual are greater than the maximum that can be provided within the community aged care funding, the individual and their family are left with having to access RAC.

When families refuse consent for an ACAT assessment or discharge forms, hospitals will start charging a daily fee and have sought temporary legal guardianship of a patient in order to transfer them into RAC. The following case study (Case Study 1 Brad) details one such case. Families are often informed that once funding becomes available for alternative housing, their loved one will be removed from RAC. However there is little evidence to suggest that people in RAC are

⁷ http://www.pda.org.au/uploads/published_papers/submission%20ypinh.pdf

considered high priority for new funding packages. Once a person is living in RAC they are no longer considered the responsibility of the state disability funding body.

Case Study 1 Brad

Dianna first contacted Youngcare Connect in November 2013 to inquire about possible accommodation options for her son, Brad, who at that point had been residing in a hospital for two years. Unable to walk following an adverse reaction to medication, Brad was not able to return home, and required more assistance than his parents, Chad and Dianna, were able to provide.

Although the hospital had originally agreed to have Brad stay until he found suitable accommodation, their hospitality had long expired and they had begun to put pressure on Brad's family to take, what they proposed was suitable accommodation; aged care.

Brad's family were recently told that the hospital intended to seek temporary guardianship of Brad to permit an ACAT assessment and enable his transition into aged care at the end of June.

Youngcare Connect has taken on the role of advocate for Brad and his family and have actively been involved in attending Brad's case management and intervention meetings with both NSW Health and ADHC. Youngcare Connect have assisted to draft letters, contact media and government agencies, and to publicise a petition to NSW Premier Mike Baird and the Hon. John Ajaka MLC to help Ben find appropriate accommodation

5.0 The Inappropriateness of Young People Living in RAC

RAC creates a multitude of problems for younger people, primarily because they were never designed to cater to their needs. Staff members in RAC are generally only trained in aged care services and are not skilled in treating people with brain or spinal injuries, as well as other acquired disabilities⁸. Instead, their training is focused on managing the end of a resident's life, rather than the day to day living of a younger person with a disability. Care is centred on personal and intimate services and therefore leaves little opportunity for community participation, recreation or rehabilitation.

⁸ http://www.pda.org.au/uploads/published_papers/submission%20ypinh.pdf



“Nursing homes have an important function in our society, but they are no place for young people with disability.” Graeme Innes

5.1 Social Isolation

The issue with younger people residing in aged care is multifaceted. The most obvious and emotionally traumatic issue is the social isolation it creates for younger people. For example, less than 54% of young people in RAC receive a visit from friends annually and even less will leave an aged care facility to visit a friend⁹.

According to the Grattan Institute, 35% of Australians over 65 die in RAC,¹⁰ and one in four will die within six months of entry into RAC¹¹. The death of a friend or family member is always profoundly upsetting, and for younger people in RAC, they are faced with this reality daily and often with little emotional support.

A 2015 submission by the Summer Foundation¹² states that 27% of young people in RAC are parents to school aged children. This statistic is worthy of deliberation because it exemplifies the greater ramifications of placing people in inappropriate care situations, and the potential effects that are felt by those close to a young person in RAC, including their young children.

5.2 Financial Burden

Younger people are compelled to live in RAC when the state or territory in which they reside cannot provide adequate disability care services. This is largely due to a shortage of available funding and suitable specialist housing. However, the financial burden is absorbed not only by the federal system of aged care, but also the young person themselves, or their family. In 2014, the federal budget release also saw a change in bonded aged care services which means that new residents requiring high needs care also have to pay the bonded nursing home fees¹³. This is a means-tested fee that takes into account the value of the resident’s realisable assets and can be between \$100,000 and \$2,000,000¹⁴. It unfairly penalises younger people who are requiring care that should be provided by a state or territory funded system, and who very often have young families at home. This change in federal government policy is also punitive to those who have managed to maintain home ownership while leaving the paid work force to care for their family member and living on a carer’s pension. The following case study (Case Study 2 Lyn) illustrates this point.

⁹ Australian Institute of Health and Welfare. National Aged Care Data Clearinghouse. 2014.

¹⁰ <http://grattan.edu.au/wp-content/uploads/2014/09/815-dying-well.pdf>

¹¹ <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=10737422896>

¹² https://www.summerfoundation.org.au/wp-content/uploads/Summer-Foundation-Senate-Inquiry-Submission_lo.pdf

¹³ <https://www.dss.gov.au/our-responsibilities/ageing-and-aged-care/aged-care-accommodation-bonds-governance-standard-information-for-approved-providers>

¹⁴ <http://www.abc.net.au/news/2015-02-19/impact-of-changes-to-nursing-home-funding-becoming-clear/6144300>

Case Study 2 Lyn

In December 2014, one woman resorted to petitioning the federal government to reconsider the costs of aged care for her terminally ill husband. This is an extract from her petition;

“Ensure the cost of aged care for a parent doesn't bankrupt the spouse and children.”

My children are losing their father who at the age of 49 suffered a cerebral haemorrhage within an existing brain tumour and now requires nursing home care. My husband has multiple disabilities, requiring 24 hour care, and has terminal cancer. Please don't add financial hardship to our distress by making the cost of care for their father more than we can afford.

We were a normal hardworking Australian family with middle class salaries, a partially paid off average suburban home and an inexpensive car. We have two school aged children and have lived like most families, paying our taxes and being good law abiding citizens, assuming that if a medical tragedy struck, our compassionate society would ensure that we did not risk losing our family home due to medical expenses. Now I can see that I was wrong. For our family and for other Australian families who suffer tragic life-altering medical tragedies, the effects can be devastating.

We are now in a situation where our weekly aged care costs exceed our net family income by close to \$400 a week and I am forced to redraw money on our mortgage to pay for my husband's care.

Is it not enough that the children are losing their father? This Aged Care policy means that in time we could also lose our home. Please review this legislation so that the unique circumstances of non-aged individuals forced into aged care is considered.

According to new Aged Care policy, my husband must leave aged care for 28 days and then be readmitted into care, before a reassessment of our financial capacity to pay a RAD (or equivalent daily charge) is made. Since my husband requires 24 hour a day care, removing him for 28 days while he is so ill, would cause a great deal of distress. Please re-evaluate our family's capacity to pay for his care without insisting that he first leaves the care he needs.”

5.3 Inadequacy of Services

A significant and pressing danger for younger people residing in RAC also concerns the lack of services that RAC can provide. Since the vast majority of younger people in RAC have an ABI (61%) (refer Figure 4)¹⁵ and that chances of rehabilitation are highest in the first 18 months after injury, it is vital that access to appropriate therapies that promote recovery is provided¹⁶. Since RAC runs on a separate funding system, residents are unable to access state or territory disability funding options the same way that other people with disabilities living at homes or disability funded supported accommodation do. Consequently, they are disadvantaged by an inability to access necessary services and therapies, and are more likely develop secondary illnesses on account of their needs receiving inadequate care. Many younger people in RAC develop pressure sores, urinary tract infections, and pneumonia¹⁷, and even worse, as the following case study demonstrates (Case Study 3 Bethany).

Case Study 3 Bethany

Mark, 26, called Youngcare Connect (YCC) in January 2014; his 25-year-old wife Bethany* had a hypoxic brain injury after a major heart attack three months earlier. She breathed unassisted and blinked, but showed no signs of facial or vocal recognition, and was unable to communicate or move any other part of her body. Mark had very minimal family support. He was also unable to work while he cared for his four young children under the age of eight.*

Bethany had been in a Western Sydney hospital for three months when pressure was put on Mark to place her into RAC. He was told there was nothing that could be done to help rehabilitate his wife and that there were no other services that could provide for her. Mark called YCC hoping to find alternative accommodation. YCC took on the role of advocate for the family, but within days Bethany was moved from the hospital into a nursing home over 40 minutes away from where her husband and children resided.

On the day that YCC was to meet Mark and Bethany at the new nursing home, Bethany was gone; this was less than five days after she had been placed there. YCC received this email from Mark:

“Hey sorry I forgot u (sic) were coming till now because Bethany was not checked on and looked after properly at the nursing home me and my kids discovered her not breathing in her room she was all crippled up and tracky (sic) was blocked due to not being suctioned now she is fighting for her life once again in ICU this time not sure if she will pull through she was doing so good and then forced into nursing home and now this.

¹⁵ <http://www.summerfoundation.org.au/wp-content/uploads/Getting-Out.pdf>

¹⁶ https://synapse.org.au/media/71265/acquired_brain_injury_-_the_facts_-_forth_edition__2013_.pdf

¹⁷ <http://www.summerfoundation.org.au/wp-content/uploads/Getting-Out.pdf>

One day young people with Bethany's condition will get a chance in life and be recognised as a living human being with an outlook not just a number or a body waiting to die but until then how many young adults have to suffer and die."

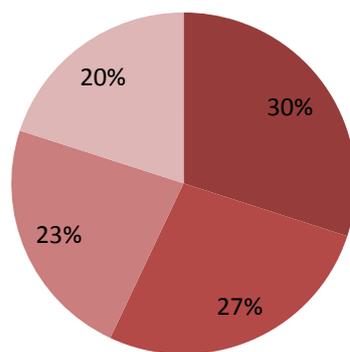
YCC received this email less than six days later;

"I'm sorry to tell you Bethany has passed away due to extensive brain damage thx (sic) for all ur (sic) concerns but that nursing home took away what life Bethany had and they will take fault if it's the last thing I do."

**All names have been changed*

Figure 4 Disability types of younger people in RAC

■ Acquired Brain Injury ■ Physical Disability
■ Neurological ■ Intellectual/ Psychiatric



6.0 YPIRAC Scheme

The Young People In Residential Aged Care (YPIRAC) scheme ran from 2006 until 2011. This scheme acknowledged the problem of relying on the already overburdened state and territory disability departments, and incorporated other government departments such as those responsible for health, aged care and housing in order to provide a collective response.

The combination of state government departments together with funding from the federal government provided a solid foundation for instigating change. However it was unanimously agreed that the funding pool of \$244 million was not sufficient to achieve complete resolution of this problem. Instead the YPIRAC scheme provided an important first step and its progress has offered insights into devising longer term solutions. Although the YPIRAC scheme was welcomed and has assisted with the transition of some younger people from aged care, its capabilities were over inflated and failed to meet its modest targets. Of the YPIRAC objectives, even the third, and undoubtedly most feasible had a modest outcome. By July 2011 only 406 people had achieved this third objective (refer Figure 5).

Figure 5 YPIRAC Objectives

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

While YPRIAC achieved a drop of 22% of new admissions for young people entering aged care, a significant number of people were unable to access their services because funding could not cover all residents. Also, of greater concern is that a decline in the number of younger people in aged care plateaued after 2011¹⁸. The shortcomings of YPIRAC were acknowledged in its 2009 Mid Term Review:

“It was originally anticipated that by the conclusion of the 2008-09 financial year, between 188-241 people would have been relocated from RAC (PO1). At the December 2008 reporting period however, the total number of YPIRAC relocated was 70.”¹⁹

Figure 6 below provides further elaboration on the reported shortcomings of the YPIRAC scheme.

Figure 6 Extract from the Mid Term YPIRAC Scheme Report

New South Wales	Original forecast to relocate between 44-88 people by June 2009, had achieved 2 relocations by December 2008.
Victoria	Original forecast to relocate 71 people by June 2009, had achieved 19 relocations by December 2008.
Western Australia	Original forecast to relocate 12 people by June 2009, had achieved 3 relocations by December 2008.
South Australia	Original forecast to relocate 24 people by June 2009, had achieved 17 relocations by December 2008.
Queensland	Original forecast to relocate between 35-43 people by June 2009, had achieved 25 relocations by December 2008.

https://www.dss.gov.au/sites/default/files/documents/05_2012/ypirac_mter_report.pdf

7.0 Youngcare At Home Care Grants

The Youngcare At Home Care Grants (AHCG) have been offered since 2009 in Queensland and now are run annually in three states (Queensland, New South Wales and Victoria). These micro grants provide between \$2,000 and \$10,000 for essential equipment, respite or home renovations to assist young people between 18 and 65 with high care needs to remain at home and avert their

¹⁸ <http://www.aihw.gov.au/aged-care/residential-and-community-2012-13/characteristics-of-clients/>

¹⁹ https://www.dss.gov.au/sites/default/files/documents/05_2012/ypirac_mter_report.pdf

high risk of entry into RAC. To date, Youngcare has distributed over \$1.5 million dollars to 383 people living at home with high care needs (refer Figure 8). The AHCG are a vital community service, responding to an area of immense unmet need and filling a critical gap in government service delivery. AHCG rounds have been generously funded by GIO in New South Wales and Suncorp Insurance, and a number of Trusts and Foundations In Queensland and Victoria.

Figure 7 At Home Care Grant applications 2012-2014 requests

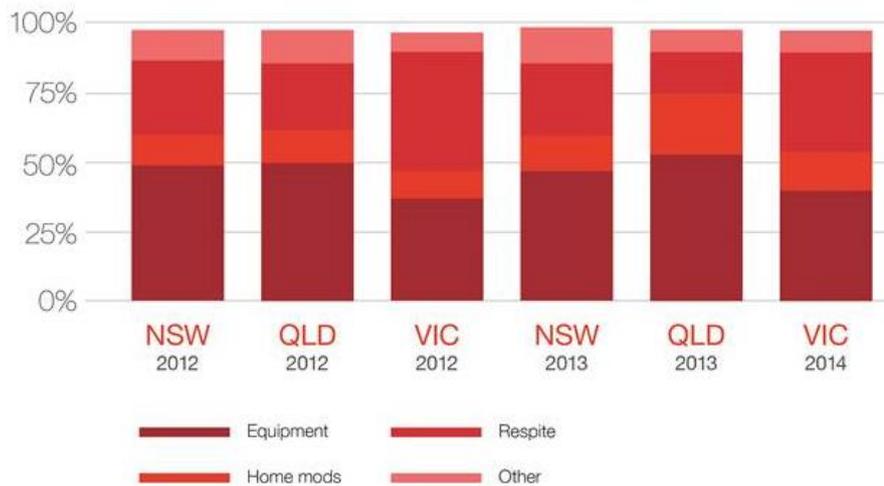


Figure 8 Funding provided through Youngcare's At Home Care Grants

Year	State	Total Applications	Successful	\$ Distributed	Unsuccessful	\$ Unfunded	Total \$ Requested
2009	Qld	19	16	\$137,291	3	\$27,150	\$164,441
2010	Qld	34	22	\$159,476.16	12	\$95,989	\$255,465.16
2011	Qld	61	21	\$87,766.73	40	\$372,972.36	\$458,676.86
2011	NSW	60	18	\$88,387.41	42	\$281,260.59	\$369,648
2012	Qld	9	7	\$48,774.84	2	\$20,000	\$69,608.82
2012	NSW	52	26	\$147,155.90	26	\$261,423.58	\$408,579.48
2012	Qld	105	16	\$99,399.20	66	\$556,884.32	\$756,283.52
2013	Vic	64	22	\$99,999.15	42	\$296,888.77	\$396,887.92
2013	Qld	58	19	\$91,664.98	39	\$299,399.26	\$391,064.24
2013	NSW	106	30	\$135,558.74	76	\$611,813.77	\$747,372.51
2013	Qld	65	45	\$239,907.39	20	173,092.61	\$413,000
2014	VIC	151	58	350,000	56	\$689,577	\$1,039,577.4
2014	NSW	61	36	\$201,484.93	22	\$174,630.80	\$427,295.94
2014	QLD	89	36	\$200,402.07	53	\$463,369	\$663,770.07
2014HS	QLD	4	3	87,483.50	1	0	87,483.50
Totals		726	383	\$ 1,501,267	445	\$3,547,727	\$5,182,208.87

The AHCG scheme has been successful in all of the states in which they have been offered. On each occasion the scheme is extremely oversubscribed, evidencing Youngcare's claim that they



target an area of unmet need, and provide immediate relief for families in dire situations. In February, 2015 Youngcare will offer its first round of funding to young people with disabilities in Tasmania, and in May 2015 applications from the Australian Capital Territory will be sought in conjunction with the New South Wales round.

8.0 Youngcare Home Soon grants

In 2014 Youngcare launched a pilot grant scheme in Queensland for young people already living in aged care and who are looking to leave and move back into their home or supported accommodation. Thanks to financial support from Suncorp Insurance, Youngcare were able to provide grants of up to \$50,000 to assist people with their transition out of RAC. This funding could be used for equipment, home modifications, attendant carer and respite services.

8.1 Lessons Learnt

The outcomes of Youngcare’s pilot Home Soon grants program have provided several insights into the complexities surrounding the exit of young people from RAC. First, we learnt about key aspects (outlined below) that were critical to a successful grant application. Second, we also learnt that reaching people in RAC without an advocate was difficult at best.

8.1.1 Combined Effort

The first and most important aspect of ensuring an applicant could safely transition away from aged care was the acknowledgment that Youngcare cannot achieve this alone. Youngcare identified four key areas that were needed before exit plans were possible: (i) an advocate, (ii) government funding, (iii) formal support, and (iv) a suitable house (refer Figure 9).

Figure 9 Combined Care



An exit plan was almost unanimously instigated by an advocate (e.g. an unpaid friend or relative of the young person in RAC). The advocate’s role was crucial, because they had intimate knowledge of the needs of the young person, and were the link between RAC and the rest of the community. Young people in RAC without access to an advocate face significant difficulties in



reaching the community to have their voice heard²⁰. This can be for a multitude of reasons, often because of speech and communication difficulties, and sometimes because of a lack of available information on alternative options. It is important to note that our experiences also highlighted the lack new recurrent funding to support a person leaving RAC and moving back to the community.

The Home Soon pilot also revealed the pivotal role that an advocate performs in campaigning for funding from state disability services on a young person's behalf. Our experience provided evidence to support the notion that a direct correlation exists between a young person's ability to secure recurrent funding packages and the persistence of an advocate to ensuring this happens. Once funding was secured from state government services, a formal disability services provider was appointed, and a combined effort from all parties took place to find suitable housing.

Youngcare found that as people in aged care are excluded from access to state-funded equipment and aids schemes, they exit RAC largely empty handed which created a huge expense and need for equipment that they could not afford. The Home Soon grants were able to assist with this financial barrier and therefore support transition home and to mitigate risks of re-entry to RAC.

The three examples listed below provide a snapshot of the different costs associated with individuals leaving RAC. These are real-life examples of individuals exiting RAC who were unable to access the state aids and equipment schemes:

- \$15,000 (most equipment and support package already in place)
- \$27,000 (identified as needing disability funded supported accommodation requiring hi lo bed, air flow mattress, sling that are required to access those services)
- \$46,000 (returning home and needing to purchase Hi-Lo bed, hoist, airflow mattress, manual wheel chair, tilt and space commode, day chair)

In summary, our experience with the Home Soon pilot scheme found that it was significantly harder to help someone transition home from aged care than it was to prevent their initial entry.

9.0 Disparity of Aids and Equipment Programs between States and Territories

After six years offering the AHCG scheme to three states and reviewing over 700 applications, some predictable trends have emerged that outline the disparity between the state and territory disability services.

Youngcare's data suggests that the need for respite in Victoria is disproportionately higher than other states in Australia. It also indicates there is a greater need for equipment in Queensland than in other states (e.g. where Hi-Lo beds and ceiling hoists are not eligible for government assistance).

Further critique concerning the disparity of aid and equipment programs between Australian states and territories is provided in Youngcare's report to the Queensland Competition Authority titled, *Medical and Disability Aids and Equipment Pricing Investigation – Submission on Draft*

²⁰ https://www.dss.gov.au/sites/default/files/documents/05_2012/rfi_summary_report_final.pdf



Report. This report highlights Youngcare’s experience and knowledge in working within the disparity of the aids and equipment schemes throughout Australia²¹.

10.0 Partnership with Griffith University

Youngcare has an active applied research agenda that aims to contribute to a national dialogue on the needs of young people with complex conditions as well as provide relevant information, support and solutions to those who need it most. Youngcare undertakes evidence-based research in partnership with the university sector to generate evidence-based models of housing, healthcare and community support that result in comprehensive and meaningful outcomes. Thanks to the knowledge partnership, Youngcare is able to inform the health, disability and housing sectors about appropriate practice in:

- New models of support and housing in the community;
- Consumer preferences for housing;
- Assessment tools for evaluating quality care provision;
- Understanding self-direction and its impact on young people;
- Developing evidence-based design specifications for housing that are consumer driven.

Knowledge generation, translation and dissemination is a key component of the Youngcare Griffith University Knowledge Partnership. Currently approximately 25 separate knowledge products comprising information sheets, reports, presentations, tools and discussion papers are being developed that will become part of the Youngcare Knowledge Bank for dissemination to a range of audiences, network and stakeholders.

11.0 Testimony – Todd

Living a life of choice and independence – a testimonial of Todd Winther, resident of Youngcare/Wesley Mission Apartments at Sinnamon Park.

I’m currently 31 years old and have a severe form of Spastic Quadriplegia Cerebral Palsy affecting all my limbs, my spatial perception, and fine motor skills. I have been fortunate enough to live at the Youngcare Wesley Mission Brisbane Apartments at Sinnamon Park for two years. I moved in at the end of 2012, after waging a ten year battle against bureaucracy of all kinds.

It all started when I turned 18, I had just finished high school and I was living with my parents on Queensland’s Sunshine Coast. Like every other person my age I desperately wanted to move away from them, and onwards to Brisbane, an hour south. Only I knew I could not. When I rang Disability Services Queensland (DSQ) to enquire about funding options for a potential move, I was promptly told that ‘You are not disabled enough to qualify for any government funding’. I had to bide my time.

²¹ <http://www.qca.org.au/getattachment/86f5cd8b-152c-4969-be6f-99957e8d8f11/Youngcare.aspx>



Over the next decade my middle aged parents tended to all my personal care needs, except for an hour each weekday from a wonderful charity organisation. This routine worked up to a point: it allowed me to complete two university degrees and to live rent free. Despite my lack of funding, I knew I was relatively well supported. But as my late teens turned into my early and mid twenties, this option became less and less viable. Instead of having a healthy adult relationship with my parents, all three of us were still stuck in the disabled/carer dynamic and living with my parents was no longer a viable option.

At the end of 2010, the three of us decided that we could no longer wait for a miracle. Practically I needed to live in Brisbane to get the most out of my studies. Emotionally I needed to have my own version of a life, with friends and exciting experiences with no restrictions. My parents also deserved to have their own life. It was not their job to look after me until they die. We waited, and then waited some more. Six months after filling out the first form, I finally got the chance to state my case.

This meeting was designed to determine if I was eligible for funding that would hopefully contribute towards the cost of my personal care for the move to Brisbane. All through the meeting I continue to wonder 'How do I tell a perfectly nice stranger who was just doing their job what the price of my freedom is?' Turns out in economic terms, the price was steep. Three months went by, and we waited again. In November 2011, DSQ came up with a temporary solution: I would receive four to five hours of in home support a day in my parents' home. This was DSQ's version of a cease fire, but it didn't solve the core problem. I still had no independence.

Then in late 2012, things had not changed and I knew something had to be done. I was emotionally tired, craving to make my own mark, and knew I couldn't live with my parents any longer. We were at the edge of the cliff for such a long time, only now I had been pushed over. I had to take drastic action. I turned up at the local DSQ office and suggested, begged and pleaded that action be taken by locking myself in their offices, refusing to come out until they found me a place to live in Brisbane. By the end of that day, I ended up at Youngcare.

The important thing to note from the above is that my experience is atypical. I'm highly verbal, and I am currently in my final year of a PhD in political science. I can advocate for myself, and I studied politics specifically so I knew how to force the hands of DSQ in situations like this. I knew I had to provide DSQ with an ultimatum. Thousands upon thousands of people with disabilities don't have such skills, don't know which buttons to press. It's these people who we should be helping.

If I didn't take my own form of assertive action I'd be dead. A victim of suicide because I felt trapped in a life I had no control over. I had no power to make my own decisions. Nowhere to escape to if I wanted freedom. No resources to live a life.

Since I moved into a Youngcare apartment on December 27th, 2012, or as I refer to it 'Freedom Day', my life has undergone a complete overhaul. What I cannot get across in mere words is how life changing this move was for my family and I. A lifelong goal for my Mum, Dad and I was reached.



People told me constantly through my childhood that my independence would come; I never truly believed it would happen. To me the dream always remained a distant hope, one in which I was not confident in taking. I did not think I could cope on my own without the distant gaze of parental supervision, the ever-reliable cushion that had helped me survive. Now I am.

The move has also allowed many social and recreational opportunities that I previously had not had access to. I have attended and participated in both the Brisbane Writers and Film Festivals. In April 2013 I was able to meet Tegan and Sara, my musical heroes. This was only the peak of many concerts I've attended since Freedom Day. I have even managed to catch some live theatre too. On average I have been going to the cinema once a fortnight. It is a simple pleasure I cherish every time I go.

I can do what I want, when I want, how I want. And this why Youngcare's model of living should be the template by which all other accommodation facilities for young people with disabilities should follow. Young people without disabilities take for granted their freedom. The ability to stay out late, get pissed, pick up a girl (or three), take her (or them) home, and wake up the next morning with a stupid self-congratulatory grin on their face.

It is marvellous to go to bed when you want, not when someone else is tired. I now go to bed without it being contingent on someone's schedule. This is what true independent living should and must do. I have had the benefit of these gifts. Others across the country should too.

12.0 Solutions

While it is widely acknowledged that the removal of all people under 65 from RAC will take considerable time to achieve, there are long term changes that need to be made as well as immediate changes that need to be implemented imminently to alleviate some degree of disadvantage that young people in RAC presently face.

12.1 Short Term Solutions

Younger people with disabilities in aged care are doubly disadvantaged, because they are socially isolated from their peers, and also ineligible to access state-funded equipment and aids schemes while residing in aged care. Very little emphasis is placed on long term rehabilitation equipment for residents that are typically in their twilight years. Urgent legislative changes should support people who are under 65 and currently in aged care, or who will reside in aged care before this problem is resolved to access state funding aids and equipment schemes. This change could potentially allow for an alleviation of services in future years and provide greater comfort and quality of life for younger people in RAC.

A similar situation can be seen in the inability of younger people to access substantial allied therapies and social services while residing in RAC. While we can identify the dominant problems that younger people face in this type of accommodation, social isolation, access to aids, equipment and inadequate therapeutic services, there really is no legitimate reason why these residents should not be eligible from accessing the same services as their peers who are living in



the greater community. State funded services should extend to all residents under the age of 65, irrespective of where they reside.

People under 65 who reside in aged care, do so predominately because of an inability of the state funded disability services to provide adequate care. It is both unreasonable and unjust that they are required to pay for the bonded care in an aged care facility. A change in policy to disqualify younger people from being subjected to this payment would help to ease the financial burden of people who are largely living on a disability pension. The following case study (Case Study 5 Lisa) highlights the present challenge of the requirement to pay for bonded care in an aged care facility:

Case Study 5 Lisa

In September 2014 Steve called Youngcare Connect (YCC) to seek some information and support for his situation. Steve's wife Lisa* is 49 and has Spinal Cerebella Ataxia, a progressive neurological disease. Steve had cared for Lisa for the past 15 years as well as bringing up their two children who were six years and three-months-old when Lisa was first diagnosed.*

Steve was Lisa's full time personal carer for 15 years. Because respite facilities require all patients to have had an ACAT assessment, the first time Steve had respite from his role as a carer was in 2011 after Lisa was finally assessed. Since the assessments are based on age not the level of care needs, and Lisa was only in her 40s, there was hesitation in allowing this assessment to go ahead. Legislation surrounding aged care was never designed to cater to people under 65, and yet people in Lisa's situation are left with no alternatives.

In August 2014, Lisa was admitted to hospital with an exacerbation of her condition, while in hospital her needs were assessed as too high to return home. The Queensland State Department of Communities, Child Safety and Disability Services did not have any current capacity to care for Lisa's needs so Steve was left with no option but to relinquish the care of his wife into RAC.

It was the hardest day of Steve's life.

Recent changes to aged care legislation meant that Lisa's care in the nursing home would be means tested to determine the costs.

Steve and Lisa had planned for their retirement prior to Lisa becoming unwell and they have a house plus a rental property and a section; these have been described by Centrelink as realisable assets which means that Steve falls outside the threshold and has to either pay a bond of over \$450,000 or daily care fees plus accommodation costs. This amounts to over \$1,650 per fortnight. While Steve does not have an income that could meet those costs, he will be faced with selling their family home to cover the bond.

Steve still plays an active role in caring for his wife; he is there every day to take Lisa to appointments, assists with feeding, and her personal care. However, since Lisa no longer lives at home with Steve, he is unable to claim a carer's pension, and is also unable to seek

fulltime employment due to his continued commitment to his wife's needs. This leaves the father of two in an impossible position. In Steve's words:

"I feel at a loss of what to do, I have more costs going out than I have money coming in; it is extremely stressful on me and my children, we want to put on a brave face for Lisa so she is not worried about things, but it gets harder and harder to keep this from her."

What makes this case more distressing is that one of Steve's young daughters is beginning to show the first signs of Lisa's illness. This makes the selling off of his assets particularly devastating for Steve who is worried she will be unable to work and provide for herself in the not-too-distant future.

Steve has written to the Department to seek dispensation due to hardship and to date this has been declined. He is currently going through the Administrative Appeals Tribunal and awaiting an outcome.

**All names have been changed, but Steve is happy be contacted by the Senate Inquiry should any of his experience require further explanation.*

12.2 Recommendations

- Allow young people in aged care to access state and territory aids and equipment schemes.
- Provide appropriate prescribed specialist services to young people in aged care such as speech, physiotherapy, occupational therapy and other allied health services
- Remove the requirement of bonded fees for young people with high care needs in residential aged care.

13.0 Access to Young People in RAC

The issue of appropriate and adequate care arrangements for people with severe physical, mental or intellectual disabilities is complex, but solutions can be found. It will take a multifaceted approach that needs to aim at diverting any new inappropriate admissions and provide alternatives to those already in aged care. The NDIS will address issues of funding, if it can be ensured that young people in or at risk of RAC have the information, support and access they need, and are enabled to undergo assessment of their individual needs that will guarantee a continuum of appropriate and specialised care. There needs to be dedicated provisions in the operating structure of the NDIS to facilitate the identification and access to young people in RAC to link them directly to the scheme.

13.1 Housing

The lack of suitable housing for people with high care needs is a widely recognised problem; however what is less acknowledged is the onus on broader society to help rectify the issue. Disability does not discriminate; everyone is only a stroke or car accident away from requiring the same level of support as most young people in RAC. As we age, those chances exceed exponentially. Building accommodation that can be made adaptable more easily is key to not only assisting all Australians to remain at home longer, but also those who have physical disabilities.



13.1.1 Youngcare Housing Solutions

For a young person with high care needs, having the right place to live is an aspiration not always realised. It is increasingly obvious that one of the biggest challenges to the success of the NDIS will be around the lack of sufficient choices in and volume of appropriate housing stock. It is a very real possibility under the NDIS that many young people with high care needs may find themselves with funding, but with limited viable accommodation options other than RAC.

Over the past 10 years, Youngcare has developed age appropriate accommodation solutions which offer young people the opportunity to exercise choice and independence. Our building program has been underpinned by a commitment to drive change and develop practical alternatives to aged care. In partnership with Griffith University, Youngcare has pioneered accommodation solutions such as one- and two-bedroom apartments, share houses and family homes, all architecturally-designed, incorporating best practice that is viable and replicable. Purpose-built, age appropriate supported accommodation as demonstrated at the Youngcare Wesley Mission Apartments at Sinnamon Park, Brisbane and Coomera on the Gold Coast, demonstrate progressive models of accommodation choices for young people with high care needs.

Youngcare is currently developing other accommodation options in Brisbane at Albany Creek and Woolloowin. These projects have been supported through the donation of land by the Queensland Government, as well as a one-off \$1 million capital grant under the EPCIT program for the Albany Creek project.

The Queensland Government has been active in supporting initiatives to provide funding and address accommodation issues in the disabilities sector through the EPCIT launched in 2012²². More recently it has also provided funding through the Provision of Accessible and Sustainable Accommodation for People with Disability in Residential Aged Care or Public Health Facilities program.

At Albany Creek, through a partnership formed with MS Queensland, Youngcare is delivering 11 apartments, eight specifically for young people with mid and high care needs and an additional three apartments which will be rented as affordable housing. As well as providing age appropriate and dignified homes for young people with high care needs, the project also provides peace of mind for elderly Queensland parent carers of adult children that their loved ones will be appropriately housed and cared for. Research undertaken through Youngcare's partnership with Griffith University – which places clear focus on collaboration with young people and their families – has provided a valuable and intimate understanding of young people with high and complex care needs. This work has underpinned the development of the evidence-based accommodation design and the model of care for the Albany Creek project which will be completed in 2016.

Similarly in Woolloowin, a share house is nearing completion stage, providing a classic 'young life' experience opportunity of share house living for four residents, as well as appropriate care and

²² <http://www.communities.qld.gov.au/disability/key-projects/elderly-parent-carer-innovation-trial>



support. Stage two will deliver four co-located family homes – an innovative model which will enable families of young people with disabilities to stay together.

The Auburn Apartments in Sydney, which are due to open in 2016, will deliver eight purpose-built one-bedroom apartments adjacent to the St Joseph's Hospital at Auburn for the critical target group of young people in nursing homes and those at risk of placement in RAC. To be run in conjunction with St Vincent's Health Australia (SVHA), it will be a purpose-built development in a priority inner-city location. The project will be delivered utilising \$1.5 million of New South Wales Government capital funding; corporate donations; trust, foundation and philanthropic funds; together with a significant level of in-kind contributions from the construction industry.

Youngcare has shown an ability to rally and work collaboratively with the community, corporate partners, non-government organisations and governments, to deliver innovative and specialised supported accommodation options based on principles of social inclusion, quality medical and multi-disciplinary care and self-determination. Moreover, our evidence-based design and model of care are valuable tools and resources for consumers, service providers, and investors to draw on to develop appropriate, best practice services that will make a difference to the lives of young people with high care needs.

These examples of quality practice notwithstanding, the housing and construction sector and the disability support sector have each identified their own priorities for what represents “good care” or “good housing” solutions and a cross-sectoral approach has so far been difficult to achieve on a broader scale. In the absence of a whole-of-sector approach and/or strategic investment partnerships that can operate across sectors, accommodation for young people with complex needs will continue to reflect traditional, siloed approaches and expert-driven problem solving.

13.2 Addressing Funding Misalignment

Though lack of available funding is generally considered one of the root causes of young people in RAC this is not always correct. There are many young people with permanent disabilities currently residing in hospitals and rehabilitation units because there is nowhere suitable for them to go, and their families have resisted pressure to send their loved ones into the aged care system. By comparing and contrasting the costs of hospital care to disability care, either at home with an attendant carer, or in supported accommodation, an exorbitant difference is apparent. The cost of daily care in an Australian hospital can be as high as \$2,195²³ which equates to \$801,175 annually. Considering the maximum allowance for high care needs in the NDIS budget is \$606 per day, which equates to \$221,540²⁴, there is no apparent reason why a lack of funding should be the key issue. Therefore, it is more accurate to suggest that the distribution of funding between government departments is instead misaligned.

²³ http://exwwwsvh.stvincents.com.au/index.php?option=com_content&task=view&id=515&Itemid=574

²⁴ http://www.ndis.gov.au/sites/default/files/documents/price_list_nsw_20may20142.pdf

13.3 Community and Corporate Appeal

From Youngcare’s experience, it is possible to collaborate across government, non- government, corporate and the philanthropic sectors to provide innovative solutions for young people with high care needs. More appeal for cooperates to attract greater contributions should be seen as a priority to enhance future projects that can achieve overwhelmingly positive outcomes.

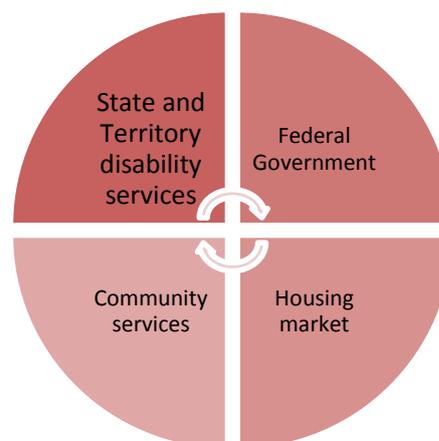
13.4 Recommendations

1. That a federal government funded disability housing innovation program be established that would call for projects from the private and the not-for-profit sector to provide accommodation solutions for young people with high care needs per example Elderly Parent Carer Innovation Trial (EPCIT) program.
2. Capital from these sectors initial funding could be leveraged and provide appropriate housing options for the young people currently living in RAC or at risk of living in RAC, that better reflect the choice in accommodation available in the general population. Such initiatives will stimulate the development of more evidence-based quality housing outcomes and will stand as viable, replicable models to be adopted by the housing, construction and disability support sectors as well as mainstream housing developers, for growth in appropriate choices and volumes of accessible housing stock.
3. Building regulations be amended to ensure there is consistency across Australia. Regulations should also stipulate that all new buildings must comply with simple design innovation to enable easy conversation of all new homes such as increasing the minimum width with of doorways to accommodate wheelchair access.

13.5 Discord between State and Federal Government Services

A lack of clarity for responsibility between state and federal government departments cannot go unmentioned. In order to address this issue adequately a combined approach must necessarily include both state and federal funded agencies such as:

- Disability services
- Health services
- Mental health services
- Departments of housing
- Commonwealth Department of Family and Community Services
- Building and planning departments





There could be a case to establish dedicated roles to coordinate care between all stakeholders that ensures a greater accountability of the persons needs being addressed appropriately. As Case Study 5 describes the need for a coordinated approach to a person's care at critical points may go a long way to diverting inappropriate admission into RAC.

Case Study 5 Justin

In early September, Youngcare Connect (YCC) received a call from Western Australia (WA) by a concerned family friend of an 18-year-old man who had been recently hospitalised. Justin, who suffers from acute anxiety, bi-polar disorder and autism, had a history of self-injurious behaviours which had worried his family and friends.

There had been many attempts to help Justin in to supported accommodation from his family, where he would have full time support and care, but the Disability Commission in WA, had repeatedly assessed Justin as being able to live independently.

The only support they were able to access was in an aged care facility, where Justin attempted suicide.

A family friend called YCC in an effort to see how Youngcare may be able to help the family to get the Disability Commission to reassess Justin again and have him properly cared for in a supported environment.

YCC assisted Justin's family to draft letters to Helen Morton, who is the head of Disability Services in WA, along with Justin's local, state and federal MPs, and also to direct Justin's family in the direction of a state-funded advocate in WA.



14.0 Contact Details

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I give consent to this submission being published:



(Samantha Kennerley)

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(Date)



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