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YOUNGER PEOPLE IN RESIDENTIAL AGED CARE

AMY SHERIDAN FOR SHELTER NSW
STUDENT INTERNSHIP REPORT

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SHELTER NSW STUDENT REPORT – YOUNGER PEOPLE IN RESIDENTIAL AGED CARE

This report was developed over a 600-hour work placement by Amy Sheridan who was undertaking her master's in social work. It was developed for the use of Shelter N.S.W. and outlines the Australian issue of younger people living in Residential Aged Care (RAC) facilities. This report will provide a summary of the background of this issue and explain who some of these younger people are and why they ended up in RAC. The Australian system will be contextualized amongst some international examples, and some of the main funding options and issues will be explored. Finally, this report will analyse the reasons why RAC is inappropriate for younger people, and in closing, present some of the ways forward in responding to this issue, through pathways like housing, education and community.

Background

In 2019, Australia had 6048 people under the age of 65 living in RAC facilities, with an average admission rate of 42 people per week (Summer Foundation, 2019). These are people who have entered RAC due to a lack of appropriate high care facilities that can cater to their requirements as they experience intellectual, physical, psychological, or sensory disabilities (Dyer et al., 2019, p. 23). Many of these people acquired their disability during early adulthood and 80% never leave RAC once admitted (Summer Foundation, 2019, p. 13). Most younger people in RAC also report feelings of isolation and have developed secondary mental health issues like depression as a result (Callaway, 2019, p.1).

The Council of Australian Governments (COAG) recognised the issue of younger people in RAC in 2005 (*Young People Will Get a Better Deal*, 2006) and created an initiative with Young People in Residential Aged Care (YPIRAC) to attempt a unification of jurisdictions. This created a partnership between the Commonwealth government and its state and territory counterparts and enabled \$244 million of shared funding for interdepartmental collaboration in the health, disability, community services and aged care sectors at both state and federal levels (Young People in Nursing Homes National Alliance, 2008).

Unfortunately, the 5-year program fell short of expectations due to a lack of federal oversight, incapacity to reform systems, and not enough knowledge on the target group (Young People in Nursing Homes National Alliance, 2008). This necessitated the Shaping the Future Today Conference (2008), which called together related stakeholders and departments to provide updates and assess the program's progress. Young people with disabilities, health representatives, policy makers, state and federal government representatives, advocacy representatives and service providers attended. Here it was revealed that there was no clear directive in place to assure congruence amongst the

SHELTER NSW STUDENT REPORT – YOUNGER PEOPLE IN RESIDENTIAL AGED CARE

stakeholders, nor was there a clear understanding between parties regarding the target group and related care pathways.

The key outcomes of this conference were:

- to extend the initiative,
- to adjust funding delivery methods,
- prevent young people from entering RAC, including all those under 65 years,
- create an insurance scheme for future funding,
- create more rehabilitation services,
- ensure consumer involvement in decision making,
- address work force training issues,
- enable transparent evaluation strategies, and
- implement interdepartmental systemic reforms.

(Young People in Nursing Homes National Alliance, 2008)

This heralded the development of the National Disability Insurance Scheme (NDIS) and consequently the National Injury Insurance Scheme (NIIS). The NDIS Act (2013, p. 4) states that the scheme should:

- support the independence and social and economic participation of people with disability
- provide reasonable and necessary supports, including early intervention supports, for participants in the National Disability Insurance Scheme launch
- enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports; and
- facilitate the development of a nationally consistent approach, and the planning and funding of supports for people with disability.

Through this scheme there is an opportunity for specialised housing to become accessible to more younger people who might otherwise be admitted to RAC. This type of housing is being developed with 400 shared housing facilities currently under development (Dyer et al., 2019, p.23). Fern River (MSWA, 2019) is a recent example of this specialised housing offering 24/7 professional care with individualised smart home technology to enable independent and more age-appropriate living circumstances.

The Disability Discrimination Commissioner Ben Gauntlett describes younger people living in RAC as a 'significant human rights issue' (Dunn, 2019, p.6). Commissioners Lynelle Briggs and Richard Tracey both agree that the aged care system '...is a sad and shocking system that diminishes Australia as a Nation' and the Interim Report was thusly titled 'Neglect' (Royal Commission, 2019). In September 2019, the Royal Commission held a hearing in Melbourne that inquired into this issue as it related to the policy responsibilities of the aged care system, the social service system and health systems, the interfaces between the systems, the profiles and circumstances of the younger people who enter aged

SHELTER NSW STUDENT REPORT – YOUNGER PEOPLE IN RESIDENTIAL AGED CARE

care, the care they receive, the special challenges they face, and the nature of the services typically provided (Royal Commission, 2019c).

The *Neglect* Royal Commission found three main areas for immediate action:

1. The provision of Home Care Packages,
2. A reduction in the use of chemical restraint, and
3. Ceasing the flow of younger people into RAC, whilst also fast-tracking current residents out of RAC

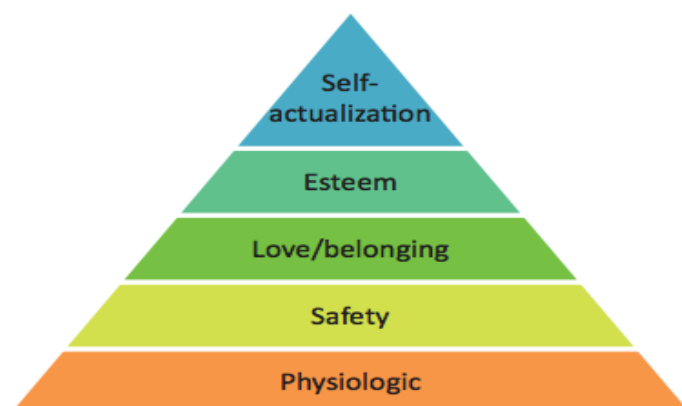
(Royal Commission, 2019).

Reasons why RAC is inappropriate for younger people

By all measures, RAC facilities are an entirely inappropriate form of housing for younger people with severe disabilities and were only ever intended as a last resort solution for this demographic.

RAC facilities are ill-equipped to cater for both the physical and mental health of younger residents, most of whom experience an extremely poor quality of life as a result. The use of RAC to house younger people has been described as the “medical system’s death row” (Knowles, 2004, p.30) or “god’s waiting room” (Summer Foundation, 2019, p. 21). The Aged Care Guide (2018) outlines how most residents of aged care facilities are in the final years of their lives, and younger people are repeatedly forced to make friends only to watch them die. This undoubtedly takes a heavy toll on the mental health of younger residents (Summer Foundation, 2019, p.21).

As well as having a poorer overall quality of life due to living in RAC, there are many cases where younger residents die prematurely due to a lack of rehabilitation and specialist clinical supports (Young People Will Get a Better Deal, 2006, p. 11). The Summer Foundation has continued to advocate for



younger people in RAC to have access to these support services to prevent harm and enable a transition back to independent living arrangements over time, however, RAC facilities are not yet required or funded to provide these specialist services as needed (Knowles, 2004; Aged Care Guide, 2018). The lack of these supports can lead to the reduced mobility of patients and poorer mental health outcomes, placing further pressure on younger residents and

SHELTER NSW STUDENT REPORT – YOUNGER PEOPLE IN RESIDENTIAL AGED CARE

compounding existing issues (Choy, 2004).

Psychological, physical and emotional well-being all determine the outcome of a patient's recovery and quality of life; however, the 2019 Royal Commission into Aged Care highlighted the fact that in many instances psychological and emotional outcomes are being entirely neglected by staff, with interactions between staff and residents being described as transactional rather than caring (Royal Commission, 2019). Over a third of residents experience severe symptoms of depression, many of whom "completely withdraw, they stay in bed- they don't see any reason to get up ... some people have talked to us about being suicidal & wanting to end their lives" (The Feed SBS, 2015).

As younger residents' social and informal support networks gradually wear thin, their mental and physical health decline, and the chances of a recovery and eventual transition out of RAC fade. This only leads to a further worsening of each of these factors, as residents often lose hope and experience a further decline in mental health, while family and friends are deterred from visiting due to the poor condition of many RAC facilities (Summer Foundation, 2019). This is a vicious cycle, and is entirely unacceptable as a way of life for so many thousands of vulnerable Australians.

STORIES OF YOUNGER PEOPLE LIVING IN RAC

RAC is clearly not a safe, secure, or healthy environment for any younger person to be living in. This is a systemic issue of inappropriate housing, which affects thousands of Australians across the country. Below are stories from just some of these people.

Peter is 48 years old and has Multiple Sclerosis, which has led to him living in RAC for the past two years. He has a wife and three children. Prior to his debilitation he was the manager of a warehouse, an active family man who loved to play soccer and lawn bowls. He came into RAC after a fall at home (Summer Foundation, 2019, p. 9).

James is 35 years old and has an acquired brain injury after an assault, which has led to him living in RAC for the past seven years. He was an ammunition technician who loved to party. He dreamt of proposing to a girl, buying a house and making a home and family. He came into RAC after deciding a group home would not suit his talkative nature, as many of the group home occupants were mute. He describes his experience: *'Within a few short weeks I became so depressed. This became so bad that it felt as though the only way to end this way of life was to commit suicide. I tried a few times* (Summer Foundation, 2019, p. 11)'.

Vicki is forty-eight and is wheelchair dependent after medical complications following a workplace accident (Meniro, 2014, p. 13). She is a mother and wife who spent 5 years in RAC and describes her

SHELTER NSW STUDENT REPORT – YOUNGER PEOPLE IN RESIDENTIAL AGED CARE

experience: *‘Nursing homes for young people take away your self-respect, dignity, and leave you where you can’t make a decision’*. Vicki has several post graduate qualifications and is a painter. She says that her wheelchair was taken away from her after she entered RAC. Staff told her that she needed to get her ‘wheelchair license’ and was bed-bound for months. She explains, *‘I would paint in my room, but the staff complained about my water colours and paints getting on the sheets, so I started painting with nail polish, it was a way of expressing grief and loss’*, going on to say that *‘the nursing home wanted me to ring the buzzer for everything, which takes away fundamental freedom of choice. When forced to live in a nursing home as a young person you not only lose your independence, but you lose all rights ... Freedom of choice, freedom of life - it is the little things, fresh air and sunlight, they are basic creature comforts you have the right to have, just the right to go outside’* (Summer Foundation, 2019, p. 10).

Anj is 33 years old and suffered severe domestic violence that resulted in a brain injury. She had dreamt of being a psychologist and enjoyed singing, socialising, and playing sport. After 5 months of rehabilitation, she then spent two and a half years in RAC. She now lives with her family and campaigns for alternatives to RAC for younger people (Summer Foundation, 2019, p. 12).

Wheels was a man in his fifties who was living in low-care accommodation for people with quadriplegia and paraplegia. He suffered complications after a tracheotomy which resulted in paralysis and had to be admitted into RAC. He describes his experience: *‘My new RAC is short of staff and at times there is only one registered nurse for 150 residents, leaving me waiting for long periods for suctioning...I’m concerned they may not reach me in time to assist me with my breathing.’* He went on to say that there was, *‘an apartment being built specifically for disabled people with everything automatic and access to 24-hour care, I’m very lucky to have the opportunity. But I’m still waiting for my NDIS plan to be approved. But now as I’ve been offered this place to live, things may start to look a bit brighter – I’m hoping – as I need to get out of here before something happens’* (Summer Foundation, 2019, p. 9). Sadly, Wheels passed away in May 2018 and his NDIS case was still under a review.

Chris is 53 years old and experienced a brain injury, which led to him being admitted into RAC. He had raised two children and worked as a chef. After rehabilitation he had no other option but to go into RAC. He describes that, *‘the nursing home felt like a prison to me’* (Callaway, 2019, p. 1). Thankfully, Chris was approved for one-off Federal funding through the affordable and accessible housing program (mentioned above). He also got approved for NDIS funding and is now living in a unit that has smart home technology and on call support. He is located next to a university and contributes to health professional students in a paid role.

SHELTER NSW STUDENT REPORT – YOUNGER PEOPLE IN RESIDENTIAL AGED CARE

Kirby is a 29-year-old who had experienced a stroke after brain surgery that left her incapacitated and requiring high level care leading to her admission into RAC (The Feed SBS, 2015). Prior to this Kirby was a teacher who had a bright career in front of her. Kirby spent a year in RAC whilst her parents used NDIS funding to remodel their house to accommodate her. During her stay staff took away her communication device and restricted her access to vital rehabilitation. Kirby describes her experience: *'I was lonely,'* she said, *'I try not to look back at it because I was very isolated and couldn't really communicate'* (Norman, 2019).

Jenny is 23 years old and has Cerebral Palsy, which has led her into RAC. She had completed high school and had many friends and creative pursuits. However, after leaving school her ageing parents had to make the gut-wrenching choice to place her where she could be cared for properly as they had become unable. She is now 60kms away from her friends and the life she once knew (Permenter, 2006, p.31).

DATA

The Australian Institute of Health and Welfare (2019) notes that younger people living in RAC often have little in common other than being under 65 years old. Each person has a unique and complex story of how they came to require high level care. Of the younger people currently residing in RAC, approximately 60% have some form of acquired brain injury, approximately 27% have a physical disability, approximately 23% have neurological issues and approximately 20% have intellectual/psychiatric conditions (Dunn, 2019). Below is a table of the specific medical conditions per state and territory (Summer Foundation 2019, p. 15).

Medical condition	AUS WIDE	NSW	VIC	QLD	WA	SA	TAS	ACT	NT
Cardio-vascular	83.4%	83.6%	84.4%	82.0%	84.1%	84.0%	81.5%	74.4%	73.9%
Nervous system	32.2%	30.5%	30.5%	32.1%	36.1%	27.8%	33.1%	37.0%	41.9%
32.6% Musculo-skeletal	23.9%	21.4%	21.3%	25.4%	24.2%	39.0%	28.1%	25.6%	28.3%
Endocrine/ Metabolic	23.7%	24.1%	22.6%	23.0%	31.1%	22.1%	12.3%	27.9%	30.4%

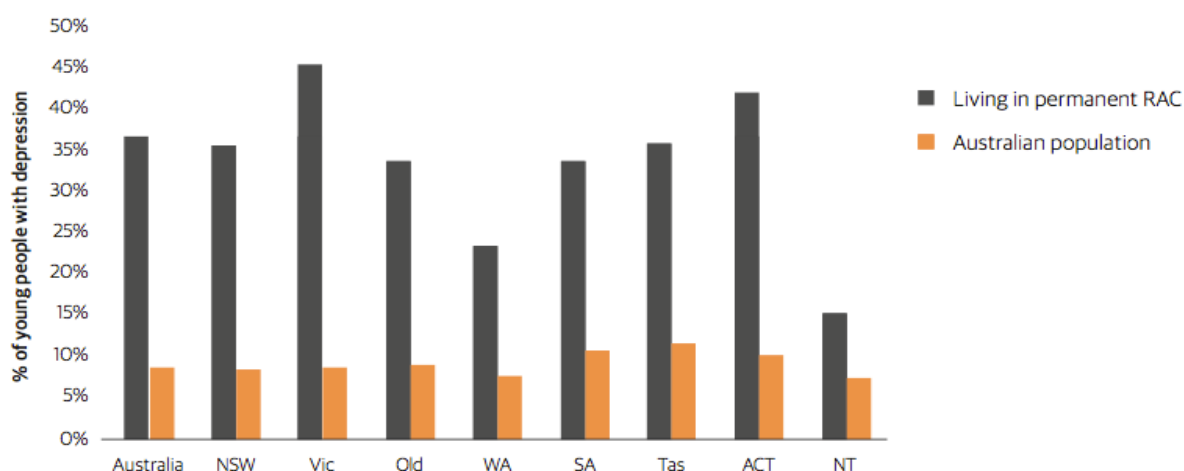
SHELTER NSW STUDENT REPORT – YOUNGER PEOPLE IN RESIDENTIAL AGED CARE

Genito-urinary	16.7%	14.5%	18.7%	13.8%	22.7%	21.0%	15.8%	20.9%	28.3%
Injuries/ Poisoning	12.6%	11.7%	11.9%	15.3%	12.1%	13.8%	8.9%	16.3%	17.4%
Respiratory	9.8%	9.2%	9.5%	10.8%	10.6%	9.8%	11.0%	16.3%	6.5%
Digestive system	8.3%	8.6%	7.0%	9.5%	9.5%	6.2%	8.2%	11.6%	6.5%
Vision impairment	5.9%	6.5%	5.0%	7.0%	5.7%	3.6%	2.7%	4.7%	17.4%
Cancers	4.9%	5.1%	4.0%	5.4%	7.0%	5.0%	4.1%	2.3%	2.2%
Skin condition	4.2%	3.6%	4.2%	4.5%	2.5%	5.7%	7.5%	16.3%	2.2%
Congenital malformatio n	3.1%	2.0%	3.8%	3.8%	2.5%	3.3%	6.2%	2.3%	2.2%
Infectious/ Parasitic	2.0%	2.4%	1.6%	1.8%	2.3%	2.4%	0.7%	2.3%	2.2%
Blood & Immune	1.9%	2.2%	1.6%	1.8%	3.4%	1.0%	1.4%	0.0%	2.2%
Ear disease	1.4%	1.5%	1.4%	1.8%	1.1%	0.7%	2.7%	0.0%	2.2%
Not Classified	59.1%	65.1%	65.4%	49.8%	38.6%	56.9%	61.6%	46.5%	43.5%
Not Specified	2.9%	2.5%	3.7%	3.1%	2.3%	3.6%	1.4%	2.3%	0.0%

Approximately 90% of young people living in RAC need one-on-one assistance with their personal hygiene. These people cannot use a buzzer, they are unable to shout out for attention and the RAC facilities are understaffed and not really equipped for high maintenance care for these patients. The Young People in Aged Care Alliance (YPACA) spokesperson even went so far as to state that *'nursing homes are perceived as dumping grounds for people that the system has given up on and, while these options remain, all people with existing disabilities or newly acquired disabilities are potentially at risk'*

SHELTER NSW STUDENT REPORT – YOUNGER PEOPLE IN RESIDENTIAL AGED CARE

(aph.gov, 2020). According to the Summer Foundation (2019), 80% of the annual turnover in younger people in RAC was by death or ageing out as most people under 65 who enter RAC do not leave before their 65th birthday (Summer Foundation 2019, p. 17). Understandably more than a third of young people living in RAC experience depression. Below the table illustrates the comparison of depression in young people in RAC per state/territory vs their counterparts not living in RAC.



Comparison of the prevalence of depression in young people who were living in permanent RAC vs those in the Australian population.

Carol Littley, mother of Kirby (mentioned above) describes her daughters experience of RAC being *'almost like a punishment'*, going on to say that *'we're putting young people in aged care because we have nowhere else in 2019 to put them'* (Dunn, 2019, p.6). The experiences these younger people are having in Australia's health and housing system are not acceptable, especially for a 'developed' and wealthy country like ours.

Why these younger people are ending up in RAC

Younger people are ending up in aged care for variety of reasons. Often, it is because there are gaps in the Australian health and housing systems. In the past, the YPACA has demonstrated that the placements of the younger people into RAC were meant to be a last resort but have *'...increasingly become the only resort'* (Parnell, 2003, p.3).'

CRACKS IN THE BUREAUCRACY

For younger people in need, it is a matter of falling between the 'bureaucratic cracks' as the State Government provides the disability services, yet the Federal Government provides RAC. As soon as these people enter RAC, they shift from the state's view and are then treated as 'aged' under the

SHELTER NSW STUDENT REPORT – YOUNGER PEOPLE IN RESIDENTIAL AGED CARE

Federal RAC programs (Knowles, 2004, p.30). The Summer Foundation (2019, p.28) stipulates that ‘on the pathway to aged care there are critical decision-making points that lead away from a return home or to other community accommodation of choice’. Where an understanding of the interface between agencies such as the NDIA and the Commonwealth Aged Care Program is required, too often it is inadequate and RAC becomes the go-to option.

HIGH CARE NEEDS AND NO SUPPORT

Younger people entering RAC are being guided towards this option due to the high care needs they have. The Australian Institute of Health and Welfare (AIHW, 2019) describes how the intake of younger people into RAC has been steady over the last decade, with demographic data showing that:

- approximately 50% are ‘older’ (60-64 years)
- of the youngest (those under 50) **approximately 10% are Indigenous** (AIHW, 2019, p. iv)
- **25% of younger people entering RAC have activity limitations in all the core activities**, which consist of: self-care, communication, movement between locations and walking around; and
- **90% of these people experience activity limitations in self-care and require assistance with daily tasks**, such as: eating, toileting and general hygiene (AIHW, 2019).

As well as having generally high physical care needs, the younger people entering RAC often also suffer from psychological trauma, as many have acquired their disability through a catastrophic health crisis, like a stroke, brain injury or a dramatic decline in a pre-existing condition (Summer Foundation, 2019). Being inappropriately placed in RAC can seriously exacerbate the mental health of these individuals, as the experience often leads to feelings of shock, bewilderment, fear, and confusion as the young person is told that they have limited time in hospital or rehab. The Summer Foundation (2019) outlines the personal turmoil that ensues after being told their time is up and describes the funneling into RAC as being a combination of ‘*no time, no knowledge and no choice*’ (p. 29).

Most commonly younger people are coming into RAC from either rehabilitation facilities or straight from hospital. In many cases RAC becomes the best option when home care services cannot be accessed or provided. In some cases, people have been evicted from group homes for various reasons, often when their needs have escalated, and they lack alternative support options. This creates a situation of overt homelessness when familial and/or social support networks are not present, forcing many people to choose between homelessness or improper housing in RAC (Summer Foundation, 2019, p. 28).

The NDIS is intended as a solution for those experiencing such severe disabilities and circumstances, yet these hopes have not lived up to the reality. Dr Morkham, the national director of the YPINHA, says

SHELTER NSW STUDENT REPORT – YOUNGER PEOPLE IN RESIDENTIAL AGED CARE

that the NDIS really needs to step up and ‘equip its obligations’ for younger people living in RAC, and that ‘we need to look further than the disability sector to solve this problem’ (Aged Care Guide, 2018). The NDIS was meant to facilitate support for people to live independently, no matter what level their ability is (Quagliotto, 2012, p. 14). At this point health care pathways lead to RAC with little to no real deliberation given to long-term rehabilitation or home care options, as the issue appears to be mainly the rigidity of the system.

LACK OF APPROPRIATE HOUSING

Housing options are far less than ideal for younger people with high care needs. There are legal and bureaucratic restrictions that do not factor in life circumstances and limit the choices of these people as they seek alternatives to RAC. Such restrictions include home modifications being denied in a rental dwellings, higher care needs housing not being fit to house families, and in the case of multiple dwellings being accessible for families, expensive double billing becomes an issue as the concession can only be applied to one bill (Gilmore, 2002, p.15).

In 2018, the Herald Sun reported that ‘each year, more than 2000 people under age 65 are admitted to nursing homes, usually because there is nowhere else for them to go (2018, p. 19)’. It is apparent that a great many of the younger people that are entering RAC are ending up here because of the limited affordable and practical housing options available to them when they need it most (Cozza, 2013, p.5). Others in rural or remote areas are choosing RAC just so as they can stay near their hometowns with family and loved ones (Young People in Nursing Homes Alliance, 2008, p. 4). Ultimately, there ‘needs to be a dramatic increase in both the range and number of supported housing options’ for young people with severe disabilities (Young People in Nursing Homes, 2008).

This is also an issue that sits clearly outside the realm of market-led solutions, as the kind of housing required is highly specialised – a cost that neither private owners or developers, or the individuals and their families themselves, are usually able to take on. As it currently stands, we simply ‘don’t have places for people to move, we don’t have the services these people need to live safely and maintain their health and wellbeing within the community’ and we do not have the ‘skilled workforce’ necessary to care for people in their homes (Aged Care Guide, 2018). The CEO of Youngcare, Anthony Ryan, has suggested that a database of existing housing options is necessary in the short term, as ‘the rapid availability of interim housing solutions is also a priority to stop younger people going into aged care (Michael, 2020)’.

Ultimately, it is the responsibility of our government (at the federal, state, and local levels) to ensure that its citizens have access to safe and secure housing. As it stands, the government’s ‘crisis-driven,

SHELTER NSW STUDENT REPORT – YOUNGER PEOPLE IN RESIDENTIAL AGED CARE

reactive, and firm focus on maintaining budgetary and fiscal responsibility, [does not meet] the demand management imperative[s] that drive disability services [and] leaves little capacity to fully meet the health and support services needs’ of the younger people in RAC (YPINHA, 2008, p.3). This statement is unfortunately as relevant now as it was when it was made by the YPINHA 12 years ago.

Contextualising the issue

AUSTRALIAN INQUIRIES AND RESPONSES

The Australian response to younger people in RAC has primarily been to initiate inquiries through the Productivity Commission, the Royal Commission into Aged Care Quality, and the Royal Commission for Violence, Abuse, Neglect and Exploitation of People with a Disability, known as the Disability Royal Commission (established April 2019).

The Productivity Commission has found that Australian families are often not prepared financially for the impact of significant disability and that Australia’s disability support system is incompetent in dealing with the needs of its consumers and suggested for there to be a new insurance scheme, which consequently heralded the NDIS (Productivity Commissioner, 2011, p. 2). The Royal Commission into Aged Care Quality revealed their findings in a report entitled ‘Neglect’, which outlined the need for a fundamental overhaul of the Australia’s entire aged care system with Commissioners Richard Tracey and Lynelle Briggs investigation stating that ‘the neglect that we have found in this Royal Commission, to date, is far from the best that can be done. Rather, it is a sad and shocking system that diminishes Australia as a nation’ (Royal Commission, 2019). The Disability Royal Commission have undertaken an investigation into the preventative measures to avoid violence, abuse, neglect, and exploitation, whilst achieving better practices in reporting, investigating, and responding to such issues, and promoting a more inclusive society to support people with disabilities to live in safety and freedom (Royal Commission, 2019a). This information will be gathered through court hearings and direct testimonies to produce their final report in 2022.

The Australian government has responded to the ‘Neglect’ report by strengthening their 2019 YPIRAC Action Plan targets, stating that by 2022 there will be no people under 65 entering into aged care and no people under 45 living in aged care, going on to promise that by 2025 there will be no people under 65 living in aged care (Australian Government, 2020, p.5). One of the first people to applaud this pledge was Dr Bronwyn Morkham, the head of Young People in Nursing Homes Alliance (YPINHA) who stated that, ‘the targets reflect the urgency of this problem and ... we are ready to work with the government to develop and implement its new strategy’ (Michael, 2020). A joint agency task force will be established to identify specialist disability accommodation and supported living options around

SHELTER NSW STUDENT REPORT – YOUNGER PEOPLE IN RESIDENTIAL AGED CARE

Australia (Michael, 2020). This is a step in the right direction, but clearly Australia has a long way to go with the overall attitudes and actions within our health system and RAC facilities.

INTERNATIONAL CONTEXT – USA

With 10% of the world's population experiencing a disability, we can look to other nations' attitudes regarding this topic and see the commonalities and differences. The USA, for example, has adopted a rights-based approach after the Americans with Disabilities Act in 1990 was created which reconceptualised disability, reframing it to be a societal rather than an individual issue (Silvers, 1996, p.209). This puts the onus back onto government and civil society to create a society that enables diversity rather than hiding the issue amongst disparate individuals. Of course, this is an ideal - a noble benchmark.

Practically, America still has major issues with its health system and many younger people fall through the bureaucratic gaps, as each state acts independently and most assisted living is privately owned and managed. This has resulted in RAC facilities taking on the responsibility of as they are publicly funded (United States General Accounting Office, 1999). America, much like Australia, is dealing with a lack of housing, which forces disabled people to live in restrictive settings (in violation of the American Disabilities Act, 1999). Most of their local housing agencies are overwhelmed in meeting the need to expand housing opportunities or modify policies and programs to cater for people with disabilities. The local housing authorities that are making disabled housing a priority are effectively utilising their time, teamwork, and creativity to tackle this issue on several fronts, despite major constraints. Ultimately, (much like Australia) legislators and advocates must discuss the country's future housing needs for younger people with disabilities to develop a coherent and effective long-term plan, however so far, this has not happened (Jackson, 2001).

INTERNATIONAL CONTEXT - EUROPE

In the EU, the focus is quite different, with comparative studies being conducted into the psychosocial well-being of people with chronic disabilities. The many determinants involved are categorised and measured as they relate to emotional well-being and general satisfaction in life.

The results reveal that people with disabilities are disadvantaged in terms of psychosocial well-being in all EU countries. They found that in the Northern countries (Finland, Denmark, Sweden, The Netherlands, United Kingdom, Ireland), the gaps between disabled and non-disabled persons are reduced compared to Eastern European countries (Russia, Ukraine, Slovakia, Poland) and that in all EU countries, the disadvantage was explained by the individual's access to support funding, rather than

SHELTER NSW STUDENT REPORT – YOUNGER PEOPLE IN RESIDENTIAL AGED CARE

the level of disability, socio-economic status, or participation in activities/work (Van Campen & Van Stanvoort, 2012, p. 839).

The European Disability Strategy (2010-2020) aims to improve social inclusion, well-being, and the fulfillment of basic human rights. Northern European countries specifically take a broader focus, as many of the studies regard quality of life, satisfaction, and well-being as fundamental. Scandinavian researchers have carried out numerous studies on the different kinds of nurse-patient interactions which shape the experience of RAC for both parties (Haugan, 2012, p. 74; Kiljunen et al, 2018, p. 1018). Findings of these types of studies were of an emotive nature rather than a fiscal one, with elements of hope, meaning of life and self-transcendence being valued as key in well-being for RAC occupants (Haugan, 2012, p. 74).

For example, a joy of life study was conducted in Norway, which revealed positive relations, a sense of belonging, sources of meaning, moments of feeling well and community acceptance all factored into the RAC experience (Rinnan et al, 2018, p. 1468). A study in Sweden, Norway and Denmark highlighted the importance of continuous, individually adjusted and supported physical activity for the maintenance of physical functions in RAC facilities (Frandin et al., 2016, p. 571). Sweden also has a housing equality program that ensures that people with disabilities can have their accommodation modified to fit their specific needs; a basic right which is funded by their local council/municipality (Sweden.se, 2019).

Another example is Italy, which has an emphasis on the positive relationship between social innovation and long-term care and is now focusing on how new innovations can promote a virtuous circle between the two (Casanova, 2020). The Italian “development cooperation system” has launched initiatives in over 25 countries (Albania, Angola, Bosnia Herzegovina, Cameroon, China, Cuba, Ecuador, El Salvador, Ethiopia, Jordan, Italy, Kenya, Kosovo, Lebanon, Libya, Morocco, Montenegro, Republic of Central Africa, Serbia, Sudan, Palestinian Territories, Tunisia, Vietnam, Yemen, Zambia) to promote the rights of people with disabilities (Cooperazione Italiana allo Sviluppo Ministero Affari Esteri, 2010, p. 4). Italy has recognized that disability is both causal and effectual in poverty as the rights of the person are compromised due to the disability. Consequently the Italian focus is on adjusting the societal attitudes towards disability as it relates to ‘all spheres of economic, cultural, political and social life’ (Italian Development Cooperation Disability Action Plan, 2013).

INTERNATIONAL CONTEXT – THE UK AND CANADA

Both the British and Canadian health care systems are broadly reflective of the Australian system, with a few key differences.

SHELTER NSW STUDENT REPORT – YOUNGER PEOPLE IN RESIDENTIAL AGED CARE

Canadian disability and housing support programs are funded by a variety of bodies including the Canada Mortgage and Housing Corporation, the Residential Rehabilitation Assistance Program, the Rent Supplement Program, the Non-Profit Housing Program, the Cooperative Housing Program, and the Canada Assistance Plan.

Both Canada and the UK share some of the same issues as Australia, such as:

- The fragmentation of service providers
- restrictive criteria for assistance
- rigid rules, standards, and a reported lack of control over individual circumstances
- administrative and attitudinal barriers
- privacy issues
- a lack of affordable housing, adequate ‘wrap-around’ support services, and a lack of personal supports.

Canada, the UK, and Australia have all identified RAC as an ‘inappropriate living environment’ for younger people. In the UK, recent research by the spinal injury charity ‘Aspire’ reports that 25% of people with spinal injuries will end up in RAC because there is simply nowhere else for them to go (Merino, 2014, p. 12).

INTERNATIONAL CONTEXT – GLOBAL

On the global stage, the UN Convention on the Rights of Persons with Disabilities (2006), adopted on December 13 by the General Assembly, introduced a new international legal and cultural standard as a vitally significant tool in fostering human rights and equal opportunities. This was not a development of ‘new’ rights to persons with disabilities, but a redefining of the existing principles within the human rights framework.

At the Convention on the Rights of Persons with Disabilities held at the United Nations Headquarters in New York, it was subsequently recognised that changing attitudes and approaches to persons with disabilities would involve shifting the view of persons with disabilities as ‘objects’ of charity, medical treatment and social protection, to ‘subjects’ with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society. The Convention adopted a broad categorisation of persons with disabilities to reaffirm that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms (UN.org, 2020). When applying these rights to the clear and urgent issue of younger people in RAC worldwide, we see a vast contrast between the global ideal and the practical reality.

Funding options for younger people in RAC

Funding is one of the key questions surrounding this issue. In the last 10-20 years there have been significant changes to the level and structure of disability funding programs at both the federal and state levels. These changes have brought some improvements, but there is still a considerable level of unmet need for disability funding across NSW and Australia.

EXISTING FUNDING PROGRAMS

A significant amount of funding has already been directed towards this issue at both the federal and state levels. In 2004, the Australian government promised \$100 million to address the issue of younger people in RAC (Clark, 2004, p.13); in 2006, over \$20 million was allocated federally (Herald Sun, 2006, p.9); and following these commitments, a further \$244 million was invested by federal and state leaders in a 5-year national program (Young People Will Get a Better Deal, 2006, p. 11; Young People in Nursing Homes, 2008, p.9).

In 2011, the Productivity Commission recommended a new national scheme to enable tailored funding solutions, later expanding this recommendation to two schemes: The National Disability Insurance Scheme (NDIS) and the National Injury Insurance Scheme (NIIS) (Productivity Commission, 2017; Treasury.gov, 2020). The Commission noted that the NIIS must be separate from the NDIS for several reasons, primarily because a specific program was needed for disability caused by catastrophic injuries, which fall under four types of accidents:

- motor vehicle accidents,
- workplace accidents,
- medical accidents and
- general accidents that may have occurred in the home or community.

The specific reasons for the separation of the two funding programs were that:

- Separation would reduce the ultimate costing of the NDIS through a fully funded and more targeted accident insurance scheme,
- the schemes could together utilise existing expertise and institutions of accident compensation schemes,
- it would create incentives to deter risky behaviour and reduce local risks that can contribute to accidents, and

SHELTER NSW STUDENT REPORT – YOUNGER PEOPLE IN RESIDENTIAL AGED CARE

- it would cover a broader range of health-related costs that are associated with catastrophic injuries, such as acute care and rehabilitation services.

The Australian Government is currently working with States and Territories to develop the NIIS as a federated model of separate, state-based, no-fault schemes that provide lifetime care and support for people who have sustained a catastrophic injury. The NIIS will build on existing State and Territory accident compensation schemes to complement the National Disability Insurance Scheme (Treasury.gov, 2020). The Inter-governmental Agreement for the NDIS & NIIS Nationwide Launch was signed off by the Commonwealth and all States and Territories at the Council of Australian Government meeting in December 2012 (NDIA 2013; Productivity Commission, 2017).

FUNDING ESTIMATES & ASSUMPTIONS

When developing the NDIS, the gross costing was based on a range of assumptions around service models. The proposed service model for NDIS assumes an acknowledgement of, and support for, existing unmet and under-met needs, including the generally untenable burden on placed on carers. The NDIS was premised on the division of care work between both formal paid care and informal care and community-based carer options. The annual cost of care and support was estimated at \$9.5 billion, with the annual cost of equipment, aids and appliances estimated at \$129 million, the annual cost of transport estimated at \$90 million, and the annual cost of home modifications estimated at \$159 million.

Several care and support services were assumed to be met by other funding sources and were not captured in the costing of the NDIS. These included

- The annual cost of income support, which was assumed to be met by the Disability Support Pension and by the Carer's Pension and Carer's Allowance
- The annual cost of homelessness, particularly the cost of emergency and transitional housing, which was also assumed to be met through other government funding
- The annual cost of hospital, medical, dental and pharmaceuticals used by people with a disability, which was assumed to be met by the health system, like Medicare and other public and private funding arrangements.
- The annual cost of RAC was assumed to be met by the programs designed specifically for this purpose.

These other funding sources also include an administration fee of 10% in the cost of the NDIS, giving a total ultimate gross annual pay-as-you-go cost of \$10.8 billion. In the case of catastrophic injury, the

SHELTER NSW STUDENT REPORT – YOUNGER PEOPLE IN RESIDENTIAL AGED CARE

service model figured a continuation of the current indemnity-based and fully funded approaches of Australian accident compensation schemes.

Ultimately, based on this model, the estimated gross annual fully funded cost of lifetime support because of injury is \$1.4 billion, with existing and potential offsets estimated at \$850 million (Disability Investment Group, 2009, p. 3). This is a significant amount of funding, covering a wide range of circumstances.

FUNDING DELIVERY & UNMET NEEDS

Unfortunately for younger people living in RAC the NDIS has fallen short of expectations, as the current procedures and structures have proven cumbersome and obstructive, with funds often not getting to the people that need them in an appropriate timeframe.

As noted in an evaluation of the NDIS from 2016, ***“over one quarter of NDIS participants need to access unfunded services.”*** The most commonly accessed supports include therapies or behaviour and specialist interventions, leisure activities outside the home, group activities in the community and transport” (VCOSS, 2017). The vast majority of these support services were found to be paid by either the patient or their family – a serious service gap for those who require the NDIS for basic support.

In response to this, the government announced an investment of \$4.7 million in November 2019 to specifically assist in the removal of young people from RAC, later launching a Joint Agency Taskforce (JATF) between the Department of Social Services, Department of Health, and the National Disability Insurance Agency (NDIA) to oversee this campaign (Australian Government: Department of Health, 2020). The new plan developed by the JATF will aim to ensure that younger people can exit RAC into more suitable accommodation through the assistance of Local Area Coordinators (LAC), who are employed to streamline and connect various services for people with disabilities (NDIS, 2020b, p.6).

The Productivity Commission (2017) stipulates that the NDIS is based on the idea that people’s support needs are individual, and the scheme should enable choice and control for people over the various services and supports they receive. The scheme is different from previous approaches in several ways, as it:

- adopts a patient-centric model of care and support
- applies insurance principles to costs
- determines funding by an assessment of individual needs rather than a fixed budget, and
- is a national scheme

(Productivity Commissioner, 2017).

SHELTER NSW STUDENT REPORT – YOUNGER PEOPLE IN RESIDENTIAL AGED CARE

However, the Young People in Nursing Homes Alliance (2011) reminds us that

“while we hope the development of an NDIS and an NIIS will significantly address this current lack [in appropriate accommodation for younger people], we also reiterate the need to trial interface engagements, the development of service pathways and other coordinated trials to get a clearer idea of need.”

Of course, funding is incredibly important, but ultimately it has no use if it cannot be directed quickly and effectively to the people who need it most. As it stands, the Australian NDIS and NIIS frameworks are not delivering funding effectively to younger disabled people, due to structural and systemic limitations. As the YPINHA explains,

“Because of the disability sector’s poorly developed understanding of lifetime care and support, its view that more funding will solve all the current system’s problems ... and the enduring lack of appropriate and functional service infrastructure ... [Australia] run[s] the very real risk that [new service pathways] will take place within the current dysfunctional disability mindset” (YPINHA, 2011, p.2).

What could be done differently?

PATHWAYS

Australia’s RAC facilities are not designed for the many high-care requirements of young people with disabilities, and it is clear that there need to be alternative pathways for these people to access high quality care and secure, appropriate, and affordable housing.

The Complex Support Needs (CSN) pathway was rolled out from November 2018, and includes NDIA liaisons and specialised support coordinators who can help to navigate the system so that Younger people avoid being placed in RAC (NDIS, 2020). This CSN pathway program needs to be reviewed and strengthened to ensure that it continues to maximise its impact and can help as many young people as possible overcome the bureaucratic hurdles that lead them to prematurely enter RAC.

The Australian Government’s ‘Younger People in Aged Care Strategy 2020-2025’ highlights the need for early and active engagement around these pathways in and out of RAC, establishing key priorities for reform across various sectors (Australian Government, 2020, p. 14). The expansion of collaborative pathways and the more effective use of NDIS funding for non-RAC alternatives are two of the primary

SHELTER NSW STUDENT REPORT – YOUNGER PEOPLE IN RESIDENTIAL AGED CARE

priorities recognised by both the government and advocates. The outcomes or ‘destinations’ of younger people with complex needs should also be a key focus, so as to better define the areas that need immediate attention (Merino, 2014). Collaboration between the sectors has been a long-standing and critical issue that is yet to be resolved since it was identified as a priority over a decade ago (Shaping the Future Today Conference Report Young People in Nursing Homes National Alliance, December 2008). Confusion over jurisdictions and the interpretation of guidelines has kept the intake statistics for young people in RAC comparable to those in 2008.

The 2008 COAG Guiding Principles, that were agreed upon by all Australian states and territories, note that younger people will only enter into RAC ‘where it can be demonstrated that all disability service options have been exhausted and there are no other services more appropriate to meet the person’s needs available’ (Summer Foundation, 2019, p.6). The experience of the younger persons pathway into RAC involves the lack of time, knowledge, and choice, with many of these people trying to access NDIS funding whilst being guided by ill-equipped staff, who do not understand the new funding system (Summer Foundation, 2019). Trevor Permenter, a professor in Developmental Disability at the University of Sydney, stipulates that the ‘one size fits all’ mentality towards people with complex needs is part of the problem as it not only removes the humanity from the person’s experience but also hinders adequate funding and access to individualised treatment and care options (Parenmeter, 2006, p. 31). Haugan (2013) agrees that there needs to be a shift from “the traditional institutionalised models towards more patient-centric care plans.”

Capacity building and self-determination must be included in the complex needs pathways. Journey mapping has been suggested as a possible two-pronged component that can both empower the individual and provide data for monitoring the complex needs pathways (Summer Foundation, 2019). The integrated approach needs to involve the younger people as masters of their own pathway. This person-centric focus and meaningful inclusion can be complimented by monitoring progress to prevent innovation being sidelined by program driven agendas. The YPIRAC Strategy 2020-2025 has taken these into account and has the younger person’s choice and control as a vital cornerstone. The NDIS was meant to enable independence for those who have complex needs, but this requires the integration of the support services to provide the wraparound care they need to support this independence. The systems that restrict opportunities for younger people to be independent need to be seriously reformed, as it is clear that building the capacity of younger people to become more independent is a crucial missing step in the current pathways available to young people with severe disabilities.

SHELTER NSW STUDENT REPORT – YOUNGER PEOPLE IN RESIDENTIAL AGED CARE

HOUSING

One most critical aspects of independence is being able to live in a safe, secure home that is appropriate for one's individual needs.

The COAG agreement (2008) states that younger people in RAC will receive enhanced Specialist Disability Accommodation (SDA) to assist them to live a more age-appropriate lifestyle, while the Summer Foundation (2019) has highlighted the need for COAG to make amendments to the National Construction Code so that all new houses will be required to be built to minimum Liveable Housing Australia Guidelines (LHA, 2020). The Liveable Housing Guidelines ensure that homes are built with according to Universal Design (UD) principles that accommodate for all age stages and circumstances of life. Features like wider doors, no steps, curb-less showers, and adjustable bench tops are all a part of the inclusive designs that are outlined by UD principles (Schwab, 2011). Assistive and smart technology can also be utilised to further enhance the liveability of homes overall (Dyer et al, 2019). The National Disability Strategy (2010-2020) suggests there are also movements towards UD in public spaces (Callaway, 2019).

Currently Australia has some accessible housing options, including:

- Young Lifestyle Care in Gordonvale Queensland (Caines Post, 2008),
- Willow Ave in Glen Waverley Victoria (Beneich, 2009),
- Ellen Buckley Place, in Inala Queensland, (South West News, 2010),
- Cootharinga in North Queensland (Townsville Bulletin, 2016),
- Kemira in Wollongong New South Wales (Hermant, 2017),
- The Disability Friendly apartments in Abbotsford Victoria (Bourke, 2015), and
- the newly built LifeBright apartments in Robina, Queensland (Gold Coast Sun, 2020).

UD accommodation, such as the developments above, increases and diversifies options for younger people who have had to live in RAC, and these principles should be applied more widely across the housing market.

There is also a clear need for more affordable housing solutions in general and more viable interim options. There is no reason why social housing cannot be the solution to this problem, and this is supported by researchers, advocates, and the disabled community. As recognized in a 2020 report by AHURI, it is clear that “integration is needed across housing and related support services...tenants with disability need better coordination between their support provider and housing provider if they are to live independently” (Flanagan *et al*, p. 64) The report also suggests the creation of specific wings or

SHELTER NSW STUDENT REPORT – YOUNGER PEOPLE IN RESIDENTIAL AGED CARE

wards of RAC for younger people whilst they are placed on waiting lists for affordable and accessible housing options.

Supported living programs need to be developed alongside housing options so that the pursuit and realisation of extended opportunities, skills, capabilities, and fulfilment in other areas of life can reflect the desires and intentions of all patients (Manroe, 1992). As a part of disentangling the NDIS from RAC, it has been suggested that there be penalties for RAC facilities that have conflicts of interest and that may be preventing other housing options for younger people and that RAC be only ever considered a short term option (Summer Foundation, 2020). The NDIA should only approve funding for RAC if the NDIS funding will not cover the costs of supported living options elsewhere and if an ACAT assessment is ever made, the NDIA should look over this for final approval with detailed explanations of their decision (Summer Foundation, 2019).

EDUCATION

Education is required for some of the fundamental shifts to occur in Australian society and health systems. Maslow's 'Hierarchy of Needs' can be used as a standard framework for ensuring adequate care and supporting wellness. Schroder & Epley (2020) aptly outline the social norm of dehumanisation that society inflicts on those with disabilities and complex needs. Education can be a powerful tool in aiding the reprioritisation of people over profit, especially when we are talking about vulnerable members of the population such as the younger people in RAC. The latest Royal Commission report of young people in RAC will be submitted with the testimonials of the younger people describing neglect, losses of basic human rights, poor treatment and attitudes of health care staff and the feelings of hopelessness that result from these experiences. The knowledge gained from these testimonials all suggest a great need for retraining staff, from the care providers in RAC facilities to the Health care professionals that are mishandling the bureaucratic aspects that reduce younger people's options with funding and access to housing.

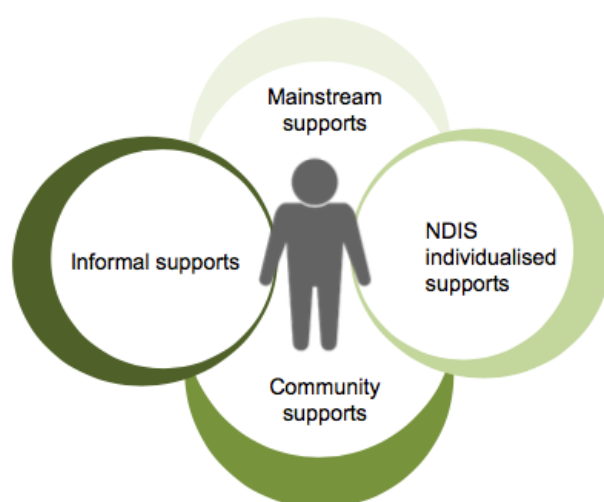
Education programs need to be developed across the board, as many specialists in the health care sectors do not have the required knowledge to ensure that younger people with complex needs are being properly cared for. The lack of knowledge around the intersection of health, disability and aged care, as well as the ad hoc provision of information from professional staff, combined with the considerable distress associated with a crisis situation could be alleviated by an appropriate education program (Summer Foundation, 2019). In a survey by the Summer Foundation (2019), of health sector staff, 65% of respondents rated their knowledge of NDIS-specific roles such as LAC and support coordination as poor, and 60% said their knowledge of NDIS access processes was poor, with nearly

SHELTER NSW STUDENT REPORT – YOUNGER PEOPLE IN RESIDENTIAL AGED CARE

3/4 of the survey group (72%) rating their confidence in how to identify and utilise opportunities under the NDIS for their clients as poor or fair.

Current hospital discharge teams also struggle with the complexities of the NDIS. They report that they require additional staff resources to meet NDIS system demands and already many funds have been wasted on poor quality support coordination. As one clinician said: 'OTs and social workers end up being [fill in] care coordinators, therapy providers and planners. It's overwhelming, and a huge amount of time for everyone' (Summer Foundation, 2019, p. 34). Below is a diagram outlining the cross-sectional support frameworks that can help enable better care for the younger people with complex needs.

Figure 2 A person-centred approach relies on supports beyond the NDIS



COMMUNITY

An individual's sense of belonging is fundamental to their well-being and community involvement is the best way to ensure this need is met. The COAG agreement specifies the requirement for younger people with complex needs to have ample opportunities to community access so as to maintain relationship and have an age-appropriate lifestyle (aph.gov, 2020). Robert Cummins & Anna Lau (2003) stipulate the positive effects that social integration and community inclusion can have on a young person with complex needs as it satiates the innate desire for connectedness. Marston et al. (2013) think that video game consoles could be a possible solution in RAC for all residents as it enables

SHELTER NSW STUDENT REPORT – YOUNGER PEOPLE IN RESIDENTIAL AGED CARE

engagement even when there are physical restrictions. This is one simple solution which could help to open up a new world of online friends that would create the sense of belonging required.

Along with policy and institutional barriers for people with complex needs, community attitudes also need to change. *“We need to help the broader community understand that a person with a disability is just like anyone else and has dreams and hopes for their future. To achieve those things, they need an age-appropriate model of housing and support so they can live in the community and pursue their goals”* (Merino, 2014, p.13). Social environments that can provide fair opportunities for young people with physical disabilities to participate together with their peers are able to provide a strong sense of belonging through teamwork, enabling exploration of social interdependence. These factors are critical for the advancement of health and well-being for younger people with complex needs and should be included in intervention design and clinical practice (Knibbe et al, 2016, p. 299). There are also alternative engagement programs such as animal assisted therapies, which research and data show have various benefits and links to enhanced well-being (Collins et al, 2006; Machova et al, 2019). There is ample opportunity for the development of engagement programs at various levels based on various needs and abilities, so as to promote community engagement and enhance younger people’s quality of life both in and out of RAC.

SHELTER NSW STUDENT REPORT – YOUNGER PEOPLE IN RESIDENTIAL AGED CARE

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