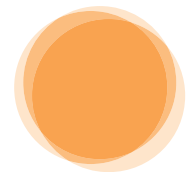




SUMMER
FOUNDATION




YOUNGER PEOPLE IN RESIDENTIAL AGED CARE:

TRUE STORIES, PRACTICAL SOLUTIONS

Summer Foundation Submission to the
Royal Commission on Aged Care Quality
and Safety

AUGUST 2019

A black and white photograph of a person in a wheelchair positioned on a set of stairs. The person is facing away from the camera, looking down the steps. The wheelchair is a motorized model with large rear wheels and smaller front wheels. The background is a dark, textured wall.

The Summer Foundation's submission to the Royal Commission into Aged Care is dedicated to Wheels*, and all the other people who have lost their lives due to institutionalised neglect and a lack of suitable support options for people with high support needs.

There is a better way.

WHEELS* – 56 YEARS OLD

Wheels had an accident when he was 16 which resulted in quadriplegia. He lived in low-care accommodation designed for people with paraplegia and quadriplegia. Here, he had his own room, ensuite and access to 24-hour care. An accident in 2015 resulted in Wheels needing a temporary tracheostomy. His recovery was slow but eventually the tracheostomy was removed and he went home.

In early 2017 Wheels had some breathing problems and it was revealed that he had picked up a virus. Further investigations found that the first tracheostomy had caused scarring on his vocal cords, which resulted in paralysis. He needed help to breathe so required another permanent tracheostomy.

Maintaining his tracheostomy came with increased nursing care requirements, which his low-care accommodation could not provide. This was the beginning of a downward trajectory for Wheels. In the space of 18 months he was moved 4 times.

Wheels was discharged from hospital to transitional care in a residential aged care facility while alternative housing was sought. None was found, and Wheels was admitted to permanent aged care.

He later moved to another aged care facility in the hope of accessing better care. "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."

In April 2018, Wheels received a conditional offer for SDA, which he was very excited about.

"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."

At the start of May, 2018 Wheels was admitted to hospital with skin integrity issues.

He never received his SDA funding. Wheels passed away in May 2018.

His case is still being reviewed by the coroner.

*indicates a pseudonym.

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INTRODUCTION

"Young people shouldn't be in a nursing home. It's a wasted life. I wasted 8 years and achieved nothing"

"I was young. I wanted to be achieving things, but nothing was possible in the nursing home. It was brutal and so unfair. The age difference was extreme and I was at a different stage of my life. It's not a good memory."

Jason Taylor* - 38 years old

The Summer Foundation welcomes the Royal Commission into Aged Care Quality and Safety, established by the Australian Government to inquire into the quality of care provided in residential and home aged care for senior Australians. Our submission addresses the Commission's priority group of young Australians interacting with the residential aged care (RAC) system.

Younger people experience unacceptable outcomes as a result of admission to nursing homes. The Australian government should be squarely focused on stopping younger people from entering aged care and supporting younger people already in aged care to return to living in the community.

The introduction of the National Disability Insurance Scheme (NDIS) means that people under 65 years with complex needs who are eligible for the scheme, have the right to funding for reasonable and necessary supports to avoid admission to RAC. The NDIS can also provide younger people already in aged care with the resources to make a choice about where they live and the opportunity to move out.

Ensuring that the NDIS is responsive to the needs of this cohort requires major policy and system changes at the Commonwealth, state and territory level.

*pseudonym

In March 2019, the Australian Government announced its plan to reduce the need for younger people to live in aged care. The *Younger People in Residential Aged Care - Action Plan* aims to help younger people in residential aged care (YPIRAC) to find alternative, age-appropriate accommodation, and to halve the number of younger people entering aged care.

The Summer Foundation has identified the key policy and systemic changes required to stop young people from being forced into aged care. Our submission covers **what** needs to change and **how** it can happen. Our recommendations are based on our extensive work with YPIRAC and the complex system interfaces involved. They are designed to contribute to the achievement of the objectives of the national *Younger People in Aged Care - Action Plan*.

With the NDIS in place, there is both an opportunity and obligation that no matter where you live, there will always be a better option than RAC.

We understand that this is a challenge, particularly in rural and remote locations. We acknowledge that residential aged care may be experienced by different population groups of younger people in different ways. Aboriginal and Torres Strait Islander people (ATSI) and culturally and linguistically diverse (CALD) groups, will need to be taken into account when designing and implementing actions and recommendations in order to avoid negative impacts. This requires direct consultation and co-design with specific groups to ensure that policies and actions are culturally safe and culturally responsive.

METHODOLOGY

Our submission is based on extensive consultation with younger people in residential aged care.

The people whose stories illustrate the realities of living in permanent residential aged care in this submission, were selected from 95 young people who participated in one-on-one conversations offered by the Summer Foundation. These were held in early 2019 to assist them to prepare their own submissions to the Royal Commission. Quotes from other participants in these sessions are also included throughout our submission. We have also drawn on previous case studies and digital story work that is directly relevant to the issue of young people in aged care. Some names have been changed at the request of the individual, an asterisk denotes a name change for the purpose of de-identifying the individual.

The Summer Foundation's intensive work with providers in the health and aged care sectors has informed our analysis of problems and solutions in systems that interface with the pathways into residential aged care. Our recommendations are based on our work developing prototypes and practice models.

ABOUT THE SUMMER FOUNDATION

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

Our Vision is that young people with disability and complex support needs live where and with whom they choose, with access to high quality housing and support options that enhance health, and wellbeing and participation.

Our Mission is to create, lead, and demonstrate long-term sustainable systems change that stops young people from being forced to live in RAC because there is nowhere else for them.

Providing the housing and support for people with complex needs and improving the interface between the disability and health sectors is necessary if we are to stop young people from being forced into RAC.

We are committed to improving policy and practice in the health system and in the NDIS so they work together as smoothly as possible.

1

KEY DIFFERENCES BETWEEN THE AGED CARE SECTOR AND THE NDIS

This chapter highlights the key differences between the aged care sector and the NDIS and explains why RAC is currently a provider of last resort for people with complex care needs.

AGED CARE – SYSTEM MATURITY

The aged care sector is relatively mature, with service coverage across all states and territories. It provides access to nursing care in RAC and at home via Community Home Care Packages (CHCPs). There are currently no age, citizenship or residency requirements to access Commonwealth aged care services.

Under the Australian Government aged care system reform, the industry is moving away from block funding providers towards a market-driven system with individualised funding. However, progress in this area is far behind the disability sector. Aged care users are required to contribute to the cost of their services based on means-testing of their income and assets. Expenditure on aged care in the 2017- 2018 financial year totalled \$18.1 billion via a range of Commonwealth subsidies and supplements.

NDIS – SYSTEM MATURITY

The NDIS commenced in July 2013 and the rollout is not due for completion until July 2020.

Anticipated annual expenditure on the NDIS at full scheme is \$22 billion. As a social insurance-based scheme, NDIS participants are not subject to means-testing. People must meet certain age, disability and residency requirements to access the NDIS.

The market for disability services overall is immature. Market provision of alternatives to RAC for younger people with complex needs, such as Specialist Disability Accommodation (SDA) and emergency short term accommodation, is particularly thin.

The interface between the NDIA and health, particularly access to funding for community nursing care, remains an area of contention. NDIS-eligible younger people may be entering RAC in order to access nursing care that they cannot obtain from other providers.

SUPPLY OF ACCOMMODATION IN AGED CARE COMPARED TO THE NDIS

The Australian Government manages the supply of residential aged care places by specifying a national target provision ratio of subsidised aged care places. At 30 June 2018, the ratio was 79.2 aged care places for every 1,000 people aged 70 years and over.

At 30 June 2018, there were a total of 207,142 operational residential aged care places. Throughout 2017-18 the occupancy rate was 90.3%, which translates to a RAC vacancy rate of 9.7%.

The NDIS Specialist Disability Accommodation (SDA) policy and pricing framework predicts that 6%, or 28,000 NDIS participants, will be eligible for SDA. The SDA market is in its infancy and currently there are very limited amounts of SDA housing options for people with high physical support needs. Existing Shared Supported Accommodation (SSA) stock that transitioned into the NDIS is generally not appropriate to meet the needs of people with high physical support needs because it was built to cater largely for people with intellectual disabilities.

In contrast, RAC is well distributed across the country. A vacancy rate of 9.7%, means that aged care accommodation is widely available in most areas. Therefore, aged care will continue to be the provider of last resort (POLR) to people with high physical support needs under the NDIS, unless there are major systemic, operational and legislative changes.

THE AGED CARE ACT 1997

The aged care legislative framework sets out the requirements to be an approved provider of Australian Government-funded aged care. This includes the allocation of aged care places, the approval and classification of care recipients, the responsibilities of approved providers, and the subsidies paid by the Australian Government. The framework also sets out the responsibilities of providers in relation to aged care quality and compliance.

The Act establishes the rules, policies and procedures to:

- Provide a sustainable system of aged care for Australia's ageing population
- Meet future demand for services
- Give older people more choice and easier access to improved care options

The 'equity of access' principle is important as the aged care system may continue to be the provider of support to people who are ineligible for the NDIS.

In chapter 5 of this submission, we make recommendations to introduce changes to the *Aged Care Act 1997* now, and over time, in response to the introduction of the NDIS. Our recommendations cover how the aged care system must be reformed in order to address the pathways in and out of aged care for younger people.

KEY POINTS

- The NDIS is a social insurance-based scheme with age, disability and residency requirements
- The aged care system can be accessed by anyone of any age, but is a market driven system, which is means-tested
- RAC is well distributed across the country, whereas the SDA market is in its infancy. This means many people with disability have access to aged care places in locations where there are insufficient NDIS SDA places.
- In 2017-18 RAC had a vacancy rate of 9.7%. RAC places are readily available. This enables RAC to function as a provider of last resort for people with complex care needs, delivering timely and responsive accommodation options compared with a much less responsive disability accommodation system in the NDIS.

2

OVERVIEW OF AUSTRALIA'S HUMAN RIGHTS OBLIGATIONS AND PUBLIC POLICY INITIATIVES

It is important to understand the failures of government to provide appropriate housing and support to people with disability within the context of Australia's commitment to the rights of people with disability. Australia is a signatory to the United Nations Convention on the Rights of Persons with Disabilities 2006. This chapter outlines what the obligations of this convention entail. It will also examine previous government commitments to addressing the issue of young people in aged care, how these commitments have failed and ways that the current government is actively seeking to make change.

UNITED NATIONS CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES 2006 (UNCRPD)

Article 19 of the convention sets out people's equal rights to live independently and to enjoy full inclusion and participation in the community. As a signatory to the UNCRPD, Australia must ensure both that people have the opportunity to choose their place of residence, where and with whom they live, and also that they are '*not obliged to live in a particular living arrangement*'.

In addition, Australia must ensure that people with disability have access to a range of in-home, residential and other community support services '*...to support living and inclusion in the community...*'.

In the following chapters, many young people tell their stories of how they were forced into 'a particular living arrangement' (i.e. RAC) because it was made clear to them that they had no choice. They also detail how their rights to live independently in the community were not protected. Australia must do better to observe the human rights of people with disability under the articles of the UNCRPD that it ratified in July 2008.

Deb Roughley's words give great clarity to the phrase 'living independently' in the community in contrast to living in RAC:

"I had the opportunity to look for some new accommodation and moved into supported independent living about 5 weeks ago. I am still getting used to my independence – a whole new place, brand new, my own room, and now I can do my crafts - making cards and scrapbooking. Now it doesn't matter whether or not I see visitors; I can go out on the balcony for meals or in the dining room – it's like being at home. I get asked about what's on the menu and can change it – I can choose when to eat. My husband will be able to stay over sometimes when we organise the bed. He's so much happier for me. I pay 25% of pension instead of 85% of pension at the aged care nursing home, I get SIL funding, I'll get rent assistance - I'm paying less than what I was paying before and getting more for it."

Deb Roughley - 58 years old

COAG PRINCIPLES

In 2008, the Commonwealth, states and territories agreed on a set of Guiding Principles to resolve the issue of young people living in aged care. Over 10 years ago, COAG acknowledged that residential aged care services are designed specifically to meet the needs of frail older people, and are not oriented to provide for the needs of younger people with disability.

It also acknowledged that the most appropriate outcome for younger people with disability is to access specialist disability accommodation and support services, and age appropriate services, rather than aged care services.

Younger people with disability, living in residential aged care or who are at risk of entering residential aged care, should have access to housing and support services that are appropriate to their needs.

The COAG agreement further states that young people in aged care will receive enhanced specialist disability accommodation to provide opportunities for community access, to maintain family and social relationships and live a more age-appropriate lifestyle. It recommends the negotiation of a regular review mechanism to jointly oversee the wellbeing of young people while in RAC.

How are governments performing against this policy?

Every week there are, on average, 42 admissions of young people to aged care. This number remains similar to the number of young people entering aged care more than a decade ago.

The COAG Guiding Principles commit to young people only entering aged care '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'.

Some success was achieved in the past when governments came together with a dedicated and focused effort. In 2006 Commonwealth and state governments jointly established and funded a 5-year Young People in Residential Age Care (YPIRAC) program, providing \$244 million. The Summer Foundation's evaluation of the Victorian Government's element of this initiative revealed that a **net reduction** of 88 people (40%) had been achieved from 2006-2011.

However, over time, as government focus shifted and ongoing investment dwindled, by 2018 these numbers had climbed back to the pre-initiative levels.¹

¹ Bishop, G. M., Zail, J., Bo'sher, L. & Winkler, D. (2019) *Young People in Residential Aged Care, 2017-2018: A Snapshot*. Melbourne, Australia: Summer Foundation.

Recent government action

In early 2019, the Australian Government made a significant step forward to end younger people being forced to live in residential aged care. In March 2019, it announced the Younger People in Residential Aged Care - Action Plan, a national action plan to reduce the number of younger people in aged care facilities.

The plan gives significant focus to outcomes, as it commits the government to specific time targets to support YPIRAC to find alternative accommodation and be able to move out of aged care within 3 and 5 years. It also aims to halve the number of younger people being admitted to RAC by 2025.

The goals of the national action plan are to:

- Support YPIRAC under 45 to find alternative, age-appropriate housing and supports by 2022, if this is their goal
- Support YPIRAC under 65 to find alternative, age-appropriate housing and supports by 2025, if this is their goal
- Halve the number of YPIRAC entering aged care by 2025

Together with the recently revised SDA rules (February 2019), and the new Complex Support Needs Pathway (November 2018), these reforms promise to support young people to avoid, and exit aged care.

The new SDA rules improve access to SDA funding, and are stimulating investment and construction of specialist housing.

A significant commitment by the national action plan is to provide YPIRAC with access to specialist NDIA planners via the Complex Support Needs Pathway. The action plan acknowledges the role of capable support coordinators who can tap into specialised knowledge on housing and support options including SDA. Participants need support coordinators with specialised knowledge and expertise to help them to exit and avoid RAC.

The plan also includes a range of policy and processes to reduce the number of younger people with complex needs being admitted into RAC because of system failures in the NDIA, and failures at all levels of government. For example, it includes actions to make system improvements aimed at: improved hospital discharge, faster NDIS access, and better planning and integrated supports.

According to the plan, by July 2019, all NDIS participants in aged care, in hospital settings or at risk of aged care admission, will have access to:

- Appropriate access and planning decisions
- Planning discussions tailored to explore and confirm housing and support goals
- Assessments and approvals for assistive technology and home modifications
- Support coordinators who can tap into specialised knowledge on housing options, including SDA

The national action plan states that it provides an integrated approach to resolve the issues that force young people into RAC. The Summer Foundation believes that the Australian Government must develop an implementation plan, in consultation with key stakeholders, to ensure that the national action plan results in long-overdue changes to the system of support for younger people with complex disability support needs.

KEY POINTS

- The UNCRPD 2006 sets out people's rights to live independently and enjoy full inclusion and participation in the community
- COAG's 2008 Guiding Principles aimed to resolve the issue of young people in aged care but government funding and focus shifted and gains that were made as a result of COAG's commitment have been lost. We have seen admission rates return to pre-initiative levels
- In 2019, the Australian Government made a renewed commitment to end younger people being forced to live in aged care. This was done by introducing the Young People in Aged Care Action Plan, revising the SDA rules and introducing the Complex Support Needs Pathway

3

WHO ARE YOUNG PEOPLE IN RESIDENTIAL AGED CARE?

Chapter 3 looks closely at the lives of young people in aged care. It examines the numbers of young people in aged care, how quickly they enter and leave, provides insight into the key characteristics of life before RAC and the destination of those that leave RAC. It also provides recent data on their progress on to the NDIS and access to NDIS supports.

The primary source of data used in Chapter 3 is customised reports from the Australian Institute of Health and Welfare (AIHW) as summarised and analysed in the Summer Foundation publication: *Young People in Residential Aged Care, 2017-2018, A Snapshot*.² (www.summerfoundation.org.au/young-people-in-rac-2017-2018).

This chapter introduces 4 main storytellers: Peter French*, Anj Barker, Vicki Wilkinson and James Nutt.

PETER FRENCH*

48 YEARS OLD – HAS LIVED IN RAC FOR 2 YEARS AND IS STILL THERE

Peter is a proud family man, he has a wife and 3 children. He played soccer and lawn bowls and had a good job managing a warehouse.

Peter and his family had bought a home in the suburbs of Melbourne, but in 2009, Peter's MS (Multiple Sclerosis) got worse and he had to give up work. Unable to pay the mortgage, they sold their home and moved into a rental further out of town.

While living there, Peter's MS further declined and he started using a wheelchair. He was still able to transfer.

In 2012, he went to a nursing home for a week of respite. He says they took good care of him. A few years later, he spent 2 weeks in respite again, in a nursing home. He was not allowed to transfer there so when he went back home he had a fall. Peter has now been in this nursing home for 2 years.

After Peter's admission to RAC, the rental house that Peter's wife was living in was sold. Peter's wife and eldest boy now live in a caravan in a caravan park, loaned from a family friend. His youngest son is living with a family friend, and his oldest son lives independently.

2 Bishop, G. M., Zail, J., Bo'sher, L. & Winkler, D. (2019) *Young People in Residential Aged Care, 2017-2018: A Snapshot*. Melbourne, Australia: Summer Foundation.



VICKI WILKINSON

LIVED IN RAC FOR 4 YEARS BEFORE LEAVING NEARLY 5 YEARS AGO

Vicki lives in Shepparton, Victoria. She has raised two children and is extremely close to both her adult daughters. Vicki married Michael while she was living in a nursing home, and they have been happily married for over 5 years. She has obtained several postgraduate qualifications, and worked in government, private, public and not-for-profit sectors. Vicki has always had an interest in art and while in the nursing home started painting with nail polish. She recently had an art exhibition.

Even though the option of a nursing home had been discussed, it was something Vicki thought would never happen. She had been in a wheelchair for 7 years when she needed an operation that resulted in 8 weeks hospitalisation and further loss of mobility. She had no choice but to go into a nursing home as her mum was too unwell to look after her. There was only one spot in their town. There was no preparation. Vicki was told by the hospital that if she didn't go into the nursing home they would discharge her without supports.

Vicki thought this was a temporary situation; later she was told she was staying there. Vicki says once you're in a nursing home there is no talk about moving out, and there is no one there to help you.

"The issue of young people being forced to live in nursing homes needs to be kept in the forefront of people's minds, this is a potential human rights issue first and foremost."

"Nursing homes for young people take away your self respect, dignity, and leave you where you can't make a decision."

Vicki's wheelchair was taken away from her for months while she was in aged care, and she was told she needed to get her "wheelchair licence". Without her wheelchair Vicki was bed-bound.

"I would paint in my room, but the staff complained about my watercolours and paints getting on the sheets, so I started painting with nail polish. It was a way of expressing grief and loss."

A black and white portrait of James Nutt, a man with a beard and glasses, looking directly at the camera. The background is dark and out of focus.

JAMES NUTT

35 YEARS OLD – LIVED IN RAC FOR 7 YEARS BEFORE LEAVING

James grew up in rural New South Wales. At 19 years old he was an ammunition technician looking forward to going to a military academy. James loved to party, was always smiling, respectful of others and quite an extrovert. He had dreams of buying a house, proposing to a girl and having a family. This all changed when he was assaulted by his boss and left with an acquired brain injury.

James spent 2 years in hospital and rehabilitation. He had been improving, but he didn't have the capacity to go home and look after himself. His needs were still high care.

James' parents were both working and couldn't be carers for him. He thought that they shouldn't have to be.

This left James with two options - a group home or a nursing home. No support was given to him in sourcing his new home. He visited 5 or 6 group homes, and found that the people living there could not communicate. As he loved to talk to people, he went into a nursing home.

James was in the nursing home for almost 7 years. He says he was "sentenced" because it felt like jail.

"It felt as though there was no longer any sense of sticking around on this earth."

"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."

A black and white portrait of Anj Barker, a woman with short dark hair and glasses, looking slightly to the left. The image is partially obscured by an orange banner at the bottom.

ANJ BARKER

33 YEARS OLD – LIVED IN RAC FOR 2 1/2 YEARS

Anj was a happy, active and popular 16-year-old living in Benalla with her loving family. She enjoyed playing sport, loved socialising and singing with friends. She was also very creative and loved working with her hands. Anj had dreams of becoming a psychologist and having a family of her own.

At age 16 she was brutally bashed to near death by an ex-boyfriend. The brain injury she incurred was so severe her family were told she would remain in a vegetative state for the rest of her life.

After 5 months of rehabilitation, she could have moved to a nursing home near her family in Benalla, but chose to stay in an aged care facility in Melbourne so she could continue to receive therapy. After 2 1/2 years in a nursing home she moved back to her family.

She says without the support from her parents and the generosity of friends and community, she would probably be dead.

Anj now campaigns for alternatives to nursing home accommodation for young people with disability, and raises awareness of relationship violence. She now works 8 hours a week and lives independently with support in Melbourne.

Anj has gone on to become the local Benalla 'Shine On' award winner, Young Victorian of the Year in 2011 and a finalist in the Young Australian of the Year. She has been to the UN and helped rewrite international law on how children are treated in third world countries. She received an OAM at this year's Australia Day Awards.

HOW MANY YOUNG PEOPLE LIVE IN RAC?

As at June 30 2018 there were 6,048 younger people with disability living in aged care.³ Many acquired a disability in their adult life. Some were admitted to aged care in their 20s or 30s and are now living with people in their 80s.

HOW MANY ARE ADMITTED EACH YEAR?

On average 42 people under the age of 65 are newly admitted to residential aged care each week.⁴ In the 2017-2018 financial year, 2,187 young people entered permanent residential aged care across Australia. These figures include young people using respite care in aged care facilities. However, it is worth noting that the risk of entering permanent aged care significantly increases with the use of respite care, with 31% of new admissions transferring from respite care to permanent aged care.

In all states the indigenous population is over-represented in RAC. In Western Australia this over representation is up to 5 times higher. We know that the geographical isolation of many indigenous communities means that there are fewer housing options to choose from. The issue of younger indigenous people with disability in aged care is complex and requires dedicated inquiry beyond the expertise of the Summer Foundation.

AGED CARE TURNOVER AND ADMISSION RATES

Over the past 10 years (2008-2018), there was an average of 2,250 admissions per year. Taking into account population increases in this period, research has shown that there has not been a significant change to the rates of admission of younger people to aged care over this time.⁵ In 2017-2018, there was a decrease in the rate of admissions, with 2,187 people being admitted to aged care, bringing this to an 11-year low. However, it is too early to tell if this decrease is the start of a trend of fewer younger people going into RAC.⁶

Over the previous 10 years, for every young person that has left aged care to go back to living in the community, there have been just over 12 people newly admitted.⁷ It is easy to see why there has been little reduction in the number of young people stuck in aged care.

The figures that represent those who leave RAC should be considered carefully, as 80% of annual YPIRAC turnover is accounted for by deaths and ageing out. This means that most people who enter aged care either don't leave before their 65th birthday, or they die there.⁸

WHAT SERVICES DID YPIRAC USE BEFORE ADMISSION?

Almost 1 in 4 younger people who entered permanent care in 2009-10 to 2013-14 had not used any other aged care beforehand⁹. Of those that had used care, the most common program was the entry-level Home and Community Care (HACC). Over 1 in 3 were admitted to RAC after using HACC services, and another 1 in 4 from other (unspecified) services. Potentially only half of the people entering RAC 5 years ago, had used aged care and/or other support services.

3 Data obtained from the AIHW Aged Care Data Clearing House, Data Request R1819_3140; data is from the 2017-2018 financial year.

4 Bishop, G. M., Zail, J., Bo'sher, L. & Winkler, D. (2019) *Young People in Residential Aged Care, 2017-2018: A Snapshot*. Melbourne, Australia: Summer Foundation.

5 Brown, M. G. & Winkler, D. (2019). *Young people in Australian residential aged care: evaluating trends 2008 to 2018*. Manuscript in preparation.

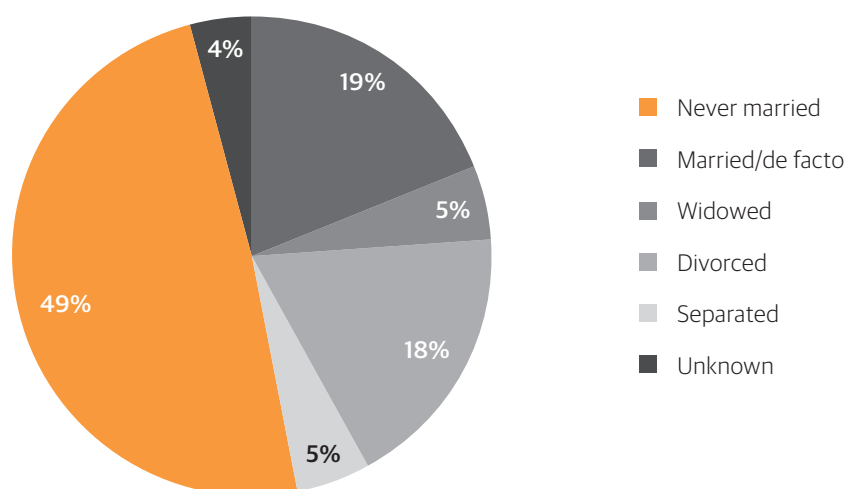
6 Ibid

7 Bishop et al.

8 Brown and Winkler op cit.

9 Australian Institute of Health and Welfare 2019. *Pathways of younger people entering permanent residential aged care*. Cat. no. AGE 89. Canberra: AIHW.

WHAT WAS LIFE LIKE BEFORE?



Marital status of young people in permanent RAC at 30 June 2018, across Australia

Around a quarter of all young people in RAC are parents to primary school aged children. Nearly half have been, or still are, in partnered relationships.

Approximately 23% of people in RAC were divorced or separated. While these figures do not reflect the reasons for the relationship breakdowns, we do know that institutionalised living does not support partnered relationships or enable people to nurture and maintain their relationships. As Peter, Vicki, James and Anj's stories tell us, the differences between life before RAC and life in RAC are stark. Many worked in rewarding careers, or were working towards achieving life goals. They were bringing up children, playing sport, getting an education, travelling, pursuing hobbies. Being forced in to RAC because of a newly acquired disability or progression of an illness is completely disempowering.

Vicki Wilkinson explains:

"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's the little things, fresh air and sunlight, they are basic creature comforts you have the right to have, just the right to go outside."

WHAT IS YOUNGER PEOPLE'S HEALTH STATUS IN RAC?

Around 90% of young people living in RAC have a mild to severe cognitive impairment, and the same number need one-on-one assistance with their personal hygiene.¹⁰ On admission, the most common medical conditions experienced by young people were cardio-vascular conditions (83%), nervous system disorders, musculoskeletal disorders, and endocrine or metabolic conditions. Only a very small portion (less than 6%) don't need assistance with their mobility.¹¹

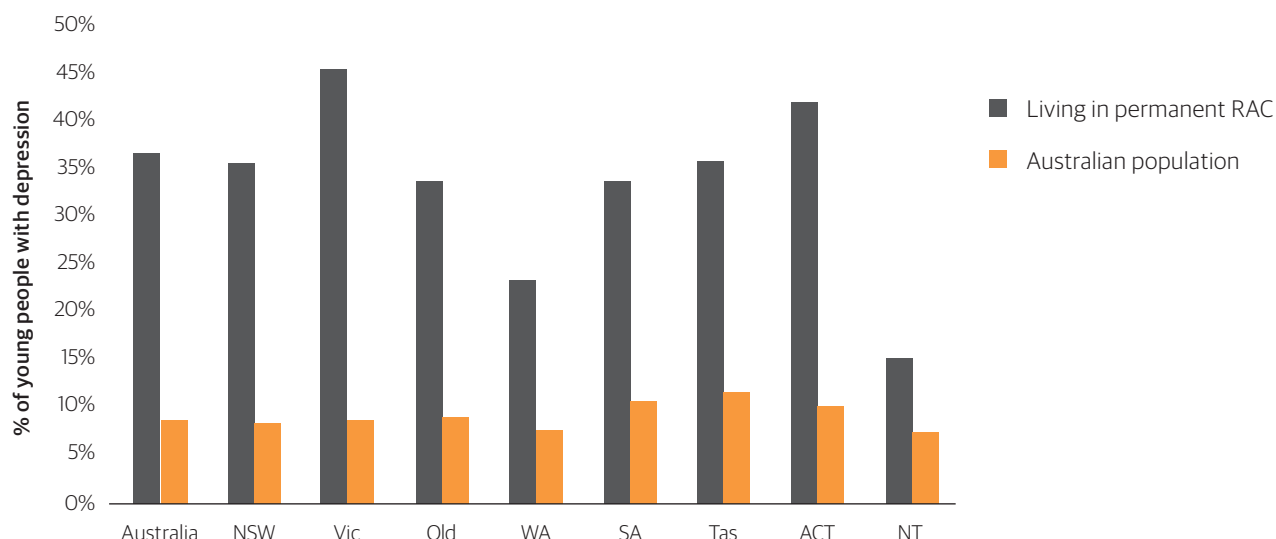
The table below illustrates the range of health conditions and the proportion of young people in permanent RAC at 30 June 2018 who were affected by specific medical conditions, assessed via ACFI based on ICD-10 classifications¹², by jurisdiction.

Medical condition	Australia	NSW	Vic	Qld	WA	SA	Tas	ACT	NT
Cardio-vascular disease	83.4%	83.6%	84.4%	82.0%	84.1%	84.0%	81.5%	74.4%	73.9%
Nervous system disorders	32.2%	30.5%	32.1%	36.1%	27.8%	33.1%	37.0%	41.9%	32.6%
Musculo-skeletal diseases	23.9%	21.4%	21.3%	25.4%	24.2%	39.0%	28.1%	25.6%	28.3%
Endocrine or metabolic disorders	23.7%	24.1%	22.6%	23.0%	31.1%	22.1%	12.3%	27.9%	30.4%
Genito-urinary diseases	16.7%	14.5%	18.7%	13.8%	22.7%	21.0%	15.8%	20.9%	28.3%
Injuries and poisoning	12.6%	11.7%	11.9%	15.3%	12.1%	13.8%	8.9%	16.3%	17.4%
Respiratory diseases	9.8%	9.2%	9.5%	10.8%	10.6%	9.8%	11.0%	16.3%	6.5%
Digestive system disorders	8.3%	8.6%	7.0%	9.5%	9.5%	6.2%	8.2%	11.6%	6.5%
Vision disorders	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 conditions	4.2%	3.6%	4.2%	4.5%	2.5%	5.7%	7.5%	16.3%	2.2%
Congenital malformations	3.1%	2.0%	3.8%	3.8%	2.5%	3.3%	6.2%	2.3%	2.2%
Infectious or parasitic diseases	2.0%	2.4%	1.6%	1.8%	2.3%	2.4%	0.7%	2.3%	0.0%
Blood and immune system	1.9%	2.2%	1.6%	1.8%	3.4%	1.0%	1.4%	0.0%	2.2%
Diseases of the ear	1.4%	1.5%	1.4%	1.8%	1.1%	0.7%	2.7%	0.0%	2.2%
Not elsewhere 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%

¹⁰ Bishop, G. M., Zail, J., Bo'sher, L. & Winkler, D. (2019) *Young People in Residential Aged Care, 2017-2018: A Snapshot*. Melbourne, Australia: Summer Foundation.

¹¹ Bishop et al

¹² The ACFI assessment allows up to three medical conditions, based on ICD-10 classifications, to be documented for each resident. If more than three conditions are present, conditions impacting most on care needs should be listed.



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

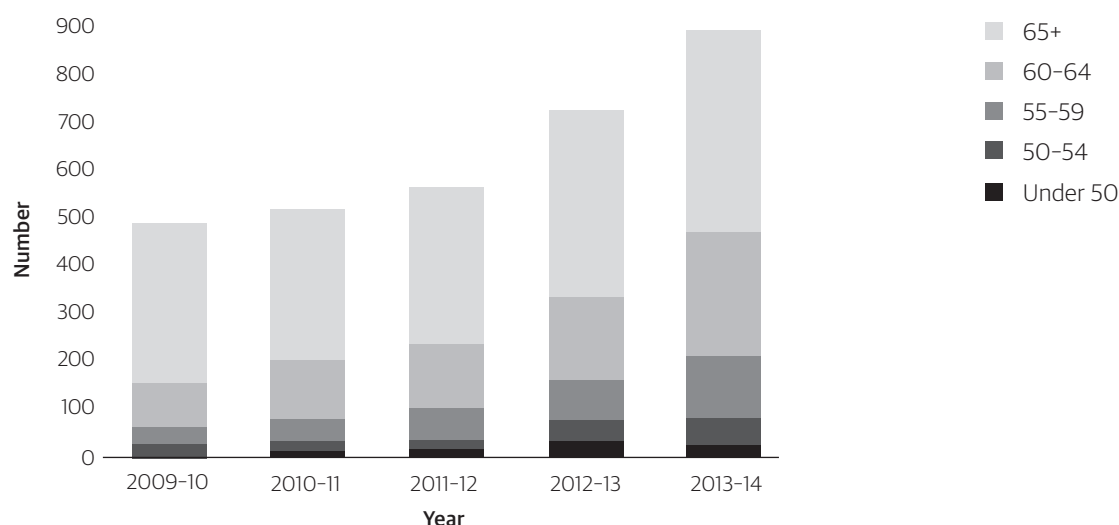
Life for a young person in RAC is characterised by isolation and loneliness. This is not just because people stop visiting, but also because the people that they are now living with are at least a generation older than them. More than a third (36.4%) of young people living in aged care have depression. A young person living in aged care is 4 times more likely to have depression compared to the rest of the population in the same age category.

HOW LONG DO YPIRAC STAY IN AGED CARE?

Half of the young people who were living in permanent RAC (51.6%) at 30 June 2018 had lived there for more than 2 years, while approximately 1 in 5 (21.8%) had lived there for 5 years or more.

The average stay for young people during 2017-2018 was 1,266 days – nearly 3½ years. Around a fifth of all young people in RAC stayed for 5 years or longer.

Just under 2,000 younger people first entered permanent residential aged care in 2009-10, 9 years later, almost 500 (25%) were still in permanent care at 30 June 2018. This rose to almost 900 (39%) for the 2,253 young people who first entered care in 2013-14 and more than half of these 900 people were still aged under 65 at 30 June 2018.¹³



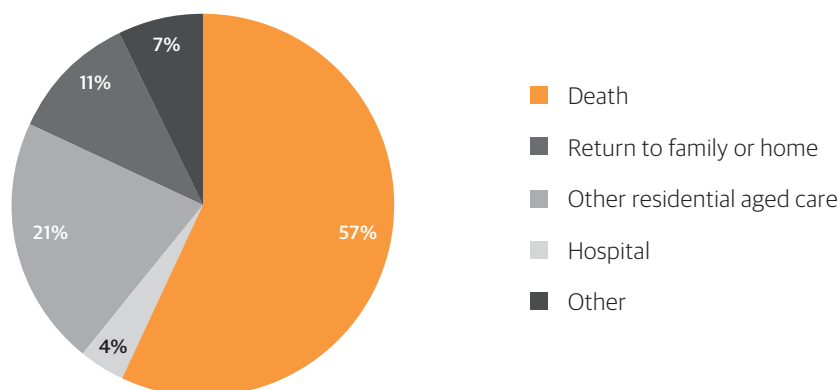
People who had first entered permanent residential aged care aged under 65 in the year 2009-10 to 2013-14 and were still in care at 30 June 2018, by age at 30 June 2018)

¹³ AIHW (2019) Pathways In - see footnote

DEATH RATES IN RAC

At the end of 2017-2018 a total of 1,853 young people left their aged care facility (by 30 June 2018). This equates to 29% of young people living in aged care. Initially this figure looks encouraging. However, of those who 'left', 1,048 left because they died in RAC. It is only when we consider why each person left aged care that it becomes clear that a large portion of young people are not actually 'leaving' RAC, they are dying there. This is 17% of the total number of young people in RAC for 2017-2018.

It is clear that for too many admission to RAC is a 'death sentence'. More than half (57%) of the 1,853 who 'exited' RAC because they died. Eighty percent of the annual turnover in YPIRAC was accounted for by deaths and ageing out. Most people under 65 who enter permanent aged care do not leave before their 65th birthday.¹⁴

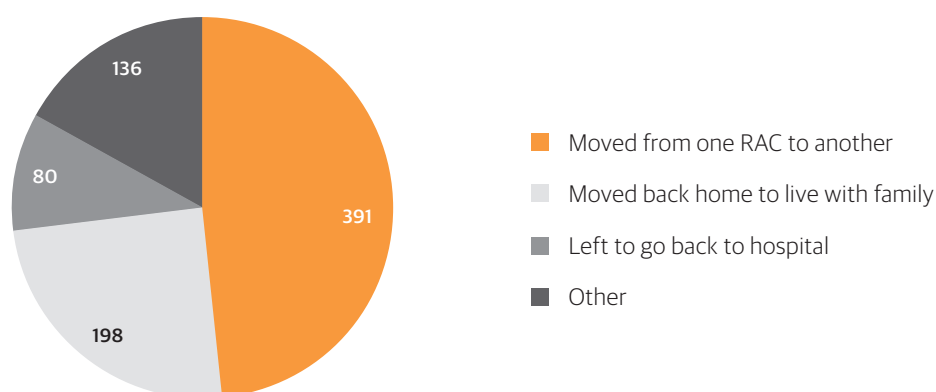


We must ask why the death rate among young people in aged care is so high. The most glaring reason is that aged care facilities are not suitable places for young people to live. Delivering appropriate care to a young person with complex care needs, living in a facility designed for an old person with aged care needs, illuminates the disconnect between the care that is needed and the care that is provided. Social isolation, combined with deteriorating health due to institutionalisation are also likely contributors.

WHERE DO YOUNG PEOPLE GO IF THEY LEAVE RAC?

In 2017-2018, 805 young people survived and left RAC to live elsewhere. However, 391 people (21%) moved from one aged care facility to another – so they didn't actually leave, they just changed facilities.

Of the remaining 414 people who moved out of RAC, less than half (198) moved back home to live with their families. Eighty left to go back to hospital and 136 were classified as 'other' - destination unknown.



¹⁴ Brown and Winkler, op cit.

HOW QUICKLY ARE YPIRAC GETTING NDIS SUPPORT?

The NDIS has the potential to stop young people being forced into RAC, but there are significant barriers to accessing the NDIS and using the funding to get out of RAC. The NDIA was slow to enrol young people who are living in RAC on to the NDIS initially, but this is improving.¹⁵

Around half the number of young people living in RAC now have active NDIS plans. In the previous 6 months, there have been as many young people in RAC who gained access to in the NDIS as there were in the 4 years prior. It is clear that the NDIA is making a concerted effort to focus on this group.

In the first 3 months of 2019, there was a significant increase in young people in RAC being enrolled in the NDIS. An average of 27 young people a month were signed up to the NDIS between January and March, bringing the total number of young people in RAC who had been assessed as NDIS-eligible to 4,093. As at 31 March 2019, 67% of YPIRAC were 'active' NDIS participants.¹⁶

Just under 1,500 young people in aged care had not tested their eligibility, and of those that had, just under 3.5% were deemed ineligible for the NDIS.

While the rates of YPIRAC accessing the NDIS are improving, another barrier is the amount of funding that young people are getting in their plans. Only a tiny portion (1.5%) of those young people in RAC with active NDIS plans have funding in their plans for specialist disability accommodation. In order to get out of aged care, 98% of young people would need to ask the NDIS for a review of their plan so they could leave aged care.

KEY POINTS

- At June 30 2018 there were 6,048 young people in RAC
- An average of 42 young people are admitted to aged care each week
- Admission rates over the previous 10 years have not changed
- 80% of people that leave RAC do so because they age out or die
- A quarter of YPIRAC are parents to young children and half are in or have been in partnered relationships
- More than a third of young people in RAC have depression
- Access rates to the NDIS continue to improve but there are some barriers associated with YPIRAC and the NDIS, particularly a lack of funding for housing

¹⁵ COAG Disability Reform Council Quarterly Report Q2 and Q3 2018-2019

¹⁶ Note that 'active' participant is defined in the Quarterly Report Q3 as 'assessed as NDIS eligible and has not left the Scheme.'

4

WHAT IS LIFE LIKE FOR YOUNG PEOPLE IN RESIDENTIAL AGED CARE?

Life in RAC for people under 65 years can be soul-destroying. Chapter 4 contains recent research evidence of just how harmful this experience can be. Each finding is illustrated here in the words of our storytellers. This chapter also looks at a literature review that outlines some of the key issues around young people entering aged care, and provides the potential solutions to these issues.

"Moving into a nursing home tore my family apart. The isolation is really hard on one level, but having choices taken away from you is worse... I was tired of watching war movies, or the elderly sitting in blue chairs, sitting under crocheted blankets with their mouths open, flies buzzing around and waiting to expire."

Vicki Wilkinson - late 40s

"It was noisy. The smell was like poo."

Sam Petersen - 35 years old

"I had asked that Michelle, as a 19-year-old girl, did not have a male nurse to shower her. Upon my arrival to her room I heard giggling, but as I entered the bathroom it wasn't Michelle, it was a male and female nurse flirting and laughing at Michelle's expense whilst she was naked, sitting in her shower chair. This should never happen. It's grossly disrespectful and undignified. I wish there was an environment where the particular needs of people were really respected."

Mother of Michelle Newland

Evidence shows that the health and wellbeing of young people is severely compromised when they live in residential aged care. A recent literature review of research studies that examine the outcomes of RAC for people under the age of 65¹⁷, illustrates the harmful impact it can have. Researchers found that YPIRAC experienced:

A SEVERE LACK OF CHOICE AROUND HOUSING

"I wanted to go home, but it was there or die. I had no choice."

Rose Stolk – 56 years old

"As there was no process for people who have had these injuries, the only place offered was in Carlton and that was not going to help us living in Geelong. I think there should be a structure built for different circumstances. They should plan for something, build accommodation for younger people, aged care is for the elderly."

Russell Bramley – late 50s (Russell's wife, Evelyn, was in RAC)

LACK OF CONTROL OVER DAILY ACTIVITIES AND ROUTINES SUCH AS ACCESS TO TIME ALONE, EATING AND SLEEPING TIMES, BODILY FUNCTIONS

"I was in a position of powerlessness but I had a voice. I knew if I wanted something done I had to initiate it and make sure it was done. In a normal day, I'd have to wait to get up, but when I did it was rush rush rush. Showers were so quick. I had to have my own checklist to make sure I was dried properly, if I didn't, then I would have skin breakdown.

"There were carers that just didn't care. For example, due to a Tracheotomy I had a dressing on my chin. Because it was not often seen to, or cleaned, one day after extreme itching I found maggots in my wound."

Lisa Jackson – 56 years old (entered RAC at 48, lived in RAC for 4^{1/2} years)

17 Oliver, S. B., Gosden-Kaye, E. Z., Jarman, H. K., Winkler, D., & Douglas, J. M. (2019). *A scoping review to explore the experiences and outcomes of younger people with disabilities in residential aged care facilities: Interim Report*. Melbourne, Australia.

LIMITED INDEPENDENCE AND SELF DETERMINATION

"The managers ran the show. They were creating rules about how we lived. I started smoking again because I had nothing to do. That's how mundane it was. I'd be placed in the lounge room with 10 other people to watch the same John Wayne movie for weeks on end. There might be one person who doesn't have dementia.

"You might make a friend or acquaintance, but the next week they're dead. A 21-year-old should not be losing the people around them like that."

"You have no choice left in your life. You have a meal menu that just keeps repeating itself. Choice of what you eat, choice of what time you get up, choice of what time you go to bed is gone. I had no choice of going out. I was there for 3 years before I was linked to a community group."

James Nutt – 35 years old

LACK OF COMMUNITY PARTICIPATION AND SOCIAL INTERACTION

"I've been in the nursing home now for 2 years. Now I'm 47, I'm still the youngest one in the nursing home by a considerable amount. There's another guy who's just come in who's 54. Just about everyone else is in their 70s or older.

"It does your head in there because you've got people in there that you speak to and try to become close to, but then they die. People die.

"I'm on to my third next door neighbour. They say it's a nursing home, but it's like God's waiting room."

"And unfortunately, that's how a lot of the other residents look at it too. The lady that's in the room opposite me has been there the whole time I have. She is 95. When she wakes up each morning she sees the purple shirt of the staff and says 'Oh, not you again. That means I'm still alive'.

"There's not a lot for a younger person to do in a nursing home. I've got alarms set on my phone for 5-to-12 and 5-to-5, so I don't nod off and miss lunch or dinner. I'm not into bingo or knitting. They have activities going a lot of the time, but they involve crocheting, embroidery or other things that I'm not interested in. They have the older generation sort of activities."

Peter French* – 47 years old

POOR MENTAL HEALTH AND LONELINESS

"Life in the nursing home was living hell. I lost all my choice and control. All I used to do when my parents weren't there was lock myself in my room and watch TV.

"Because I was the youngest person in the facility I had no-one to talk or to share interests with."

"I took up smoking again because I was bored and the nurses gave more attention to the smokers. I got to go outside more often. I was in a manual wheelchair back then and couldn't get out of my room... In the nursing home some of the nurses were very slack and didn't seem to want to be bothered. They said they had too much paperwork to do, it seems like there is more paperwork than time for clients. I mean, when you're a nurse you're meant to care about people. They only cared about their pay cheque. There needs to be a place that people want to visit. My friends did want to come and see me, but didn't because they didn't want to come and hang out in a nursing home. There was nothing there for young people to do. I couldn't have my radio up and play loud music. I wasn't even allowed to Skype home to my parents in Benalla because the nurses didn't want to be caught on the camera.

"I felt unloved, unwanted and lonely. It was horrible."

Anj Barker - 33 years old

DAMAGE TO PSYCHOLOGICAL WELLBEING

"The staff were not trained at all to look after a young person. I was not able to be taken anywhere outside of the nursing home because there were no vehicles able to carry an electric wheelchair. My care was substandard. During my time in the nursing home my carers physically, sexually and emotionally abused me. I am more than willing to talk about this abuse because the public need to know about what happened to me.

"My story needs to be heard. I tried to talk to people about my abuse and they kept telling me that they would look into it but never did."

"This abuse has caused me to distrust most people I meet and I have a huge fear and distrust of medical and care professionals."

Greg Brown - 49 years old (in RAC in his 20s)

"The fire door to the elevator was shut at 7pm each night, and so I was unable to access any other area in the nursing home, including to get outside, until 7:30 am the next morning. I was only able to drink out of the bathroom sink for example.

"Nurses never answered the call bell so if my catheter broke I had to lie in urine 'til morning."

"The bed was always infested with bugs that bit me all the time. The only relief I got was applying insect spray but it was constantly confiscated. I was covered in bites that got infected."

Brenda Evans - 52 years old

"They banned me from doing rehab in my nursing home. They weren't going to waste any of their government money, when I was just going to die anyway."

Geoff Peters* - aged in 30s

UNMET BASIC NEEDS – PRIVACY, PHYSICAL, SEXUAL, SOCIAL, NUTRITIONAL AND EMOTIONAL NEEDS

"Privacy was an issue. I had people wandering into my room every day. It wasn't their fault, they had Alzheimer's, but I couldn't lock my door. People shouting out all through the night, the constant noise. They constantly got my washing mixed up. I constantly lost stuff and found stuff that obviously wasn't mine, like underwear and they gave me a nightie. I felt the nursing home was just some place to die. There needs to be a duty of care for the company and the staff.

"I tried to tell them about one particular staff member who wiped my face with the same paper towel they wiped my bum with. It was unhygienic."

Chris LeCerf - late 50s (in RAC in early 50s)

"I loved it when my son and daughter came to visit me but I didn't want them to see me in an old persons' home. I was embarrassed, I shouldn't have been there."

"When my daughter at 8 visited me at the nursing home she used to say "it stinks". The food in the nursing home was disgusting, shocking. I didn't get any choice of what I ate just get what you were given. I didn't get any privacy at the nursing home, it was really annoying. I'd have my door closed and they would still come in, didn't knock or nothing. They'd give me tablets and just check on me. I didn't like the fact that they just came into my room they should have knocked at least. No privacy, it made me frustrated and angry. Even when my kids visited they'd still just come in. I only got to see them once a week for an hour they should have just left us."

Jackson Smyth* – 50 years old (in RAC in his 40s)

These findings are consistent with earlier research on YPIRAC, and reinforce that little has changed since the introduction of the NDIS. In an earlier submission to the 2015 Senate Inquiry into the adequacy of existing residential care arrangements available for young people,¹⁸ the Summer Foundation detailed research findings of harmful impacts that multiply over time to reduce people's capability to leave this setting.¹⁹

Some of the detrimental effects were the progressive loss of decision-making skills, withering of social networks, and a reduction in the resources needed to imagine a new home outside of aged care. The institutional culture and environment can therefore lead to the disappearance of capacity, willpower and opportunities to return to live in the community.

"It felt like survival, like I was in a prison and every day was survival of the fittest. Day after day was the same. They took 85% of my pension and with that gone I was so financially disadvantaged that I couldn't afford to go out. I could feel myself getting institutionalised, and I didn't want that."

Lisa Jackson, aged 56, was anxious about becoming institutionalised

¹⁸ Summer Foundation 2015. Submission to the Senate Inquiry into the Adequacy of Existing Residential Care Arrangements Available for Young People with Severe Physical, Mental or Intellectual Disabilities in Australia.

¹⁹ Winkler, D. et al. 2010. *Comparison of people with ABI living in two accommodation settings: Share Support Accommodation and residential aged care.* *Brain Impairment*. 11(3): 299-312

PROBLEMS AND SOLUTIONS

The research studies reviewed by Winkler et al²⁰ identified problems that need to be addressed, and potential solutions.

Firstly, a lack of alternative housing options (i.e. housing that is affordable and adaptable) is both a cause of younger people with complex disability needs being admitted to residential aged care, and a reason why they cannot leave. Some studies found that YPIRAC felt 'stuck' and had little hope of a way out of permanent aged care. The authors recommended that the solution was for YPIRAC to be discharged from rehabilitation into adapted housing. A variety of housing options must be made available.

Secondly, researchers concluded that harmful outcomes arose from the lack of availability of rehabilitation and other support services for YPIRAC. To address this, they argued that systemic changes were needed so timely rehabilitation was available, and skilled support coordination was accessible.

Third was a lack of access to independent advocacy. A solution would lie in ensuring that YPIRAC had access to independent advocates and supported decision-making, when it is required. This would enable individuals and their families to understand and navigate complex systems and enable informed decision-making.

Fourth, there was a need to address the problem of gaps in processes and procedures oriented to the wellbeing of YPIRAC. Changes in practice were needed to increase reassessment and rehabilitation opportunities, and staff education was needed to increase recognition of individual needs and choice.

Finally, the Review authors highlighted the problem of a lack of data on the ongoing health and wellbeing of YPIRAC. They identified a solution in the establishment of a review process with follow-ups. In their words: 'an effective review process would ensure that young people placed in aged care receive the ongoing rehabilitation and support required to transition to an independent living environment.'

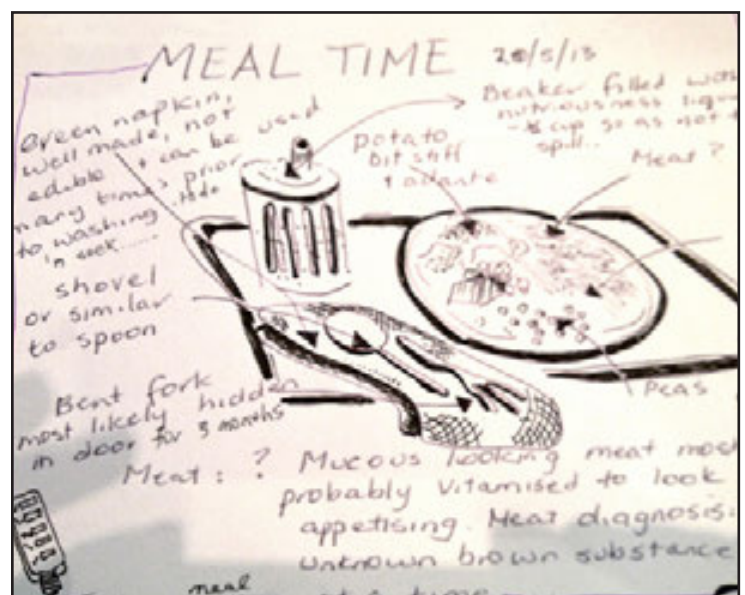
KEY POINTS

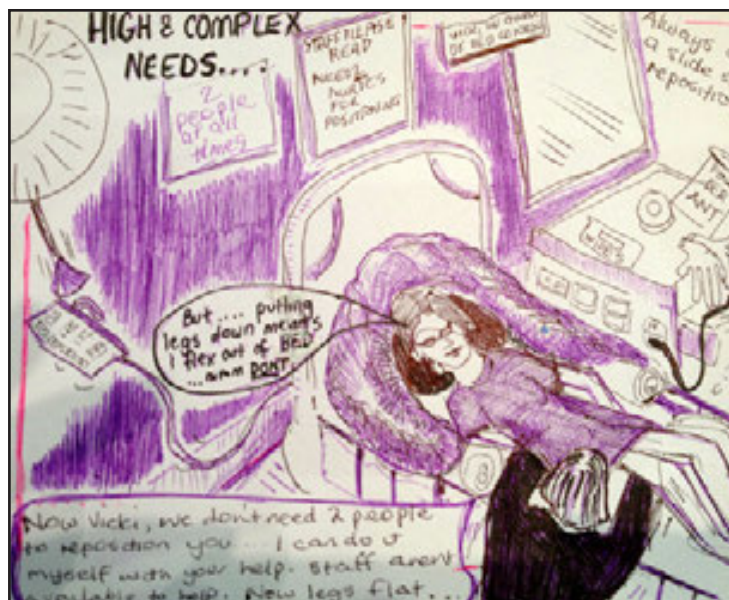
- Quality of life for young people in aged care is severely compromised
- They experience lack of choice, control, independence, self-determination, community and social life, are more likely to have depression and experience damage to psychological wellbeing
- These harmful impacts resulting from institutionalisation multiply over time, which reduces the capacity to leave RAC
- Access to skilled support coordinators and timely rehabilitation would help reduce the number of young people being admitted to aged care
- Introducing a review process where people were followed up and reassessed for rehabilitation and independent living would also assist

²⁰ Oliver, S. B., Gosden-Kaye, E. Z., Jarman, H. K., Winkler, D., & Douglas, J. M. (2019). A scoping review to explore the experiences and outcomes of younger people with disabilities in residential aged care facilities: Interim Report. Melbourne, Australia.

WHAT IS LIFE LIKE FOR YOUNG PEOPLE IN RESIDENTIAL AGED CARE?

These drawings by Vicki Wilkinson show what life was like for her in RAC.





5

PATHWAYS IN:

Why do young people end up in RAC and how can we stop more young people going in?

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. This chapter examines aspects of the pathway that young people in aged care experience: the pathway through health systems, and the pathway through the aged care system.

This chapter offers the unique perspective of the person with disability and their family and how they experience these critical decision-making points while in the health setting. Understanding how the pathways work involves an in-depth understanding of the interface between the NDIS and health systems, and the NDIS and the Commonwealth Aged Care Program. Chapter 5 covers these two major interfaces.

WHERE DO PEOPLE ENTER RAC FROM?

Admission from hospital or rehabilitation is a common pathway to RAC. In situations where young people with disability are living in the community, admission to RAC can be the result of escalating health and support needs due to a lack of access to high quality primary health services. Just under a quarter of young people who entered RAC between 2009-10 and 2013-14 had not used any other aged care before. Pathways in often consisted of a combination of home care, community-based aged care packages, respite in RAC and transition care. Almost half (46%) had used one of these programs before entering permanent RAC.²¹ (The Summer Foundation is aware that this data is not current and is seeking more recent data that is not currently available).

Other pathways to RAC can occur when tenants are evicted from group homes via health services. Also, people with complex care needs and multiple disadvantage such as homelessness, challenging behaviours and a lack of informal supports can run out of housing options when their needs escalate, as their health deteriorates.

People with disability can be more at risk of RAC admission if they have limited or absent family and/or social networks as this reduces their advocacy and informal support resources at times of crisis.

²¹ Australian Institute of Health and Welfare 2019. *Pathways of younger people entering permanent residential aged care*. Cat. no. AGE 89. Canberra: AIHW.

HOW DO PEOPLE EXPERIENCE THE PATHWAY TO RAC?

When a young person is at risk of entering aged care, it is often the result of a catastrophic health crisis such as a stroke, brain injury or a decline in a pre-existing condition. These circumstances result in shock and emotional turmoil. People in this situation described feeling "shocked, bewildered, overwhelmed, confused and frightened". In their recent research paper, Barry, Knox and Douglas chronicle the experience of the pathway into aged care for people with acquired neurological disorders.²²

The research illuminates the nuances of the pathway into aged care as experienced by young people and their families. The initial health crisis is followed by being told that they had run out of time in the health setting. Once a person is deemed to be medically stable, and therefore ready for discharge, there is pressure from the hospital to leave. This is often within the context of also being told that the only option from hospital is aged care.

The combination of emotional turmoil, being told their 'time's up', and not being given any viable alternatives to aged care, often leads to the decision to enter RAC. This decision is characterised by 3 major issues: no time, no knowledge and no choice.

NO TIME

The 'no time' issue has several dimensions. It incorporates the speed of onset of the health crisis, time pressure to make a decision quickly, and having limited time to make a sufficient recovery in order to avoid aged care.

The time pressure is evident in people feeling that they need to make a quick decision about the person's discharge destination. This is combined with the pressure to find and secure an offer of accommodation. This pressure contributes to poor decision-making, which is based on the advice of health professionals, rather than taking the time to consider the needs of the person and the possible impact of aged care.

There is also insufficient time to demonstrate the capacity for rehabilitation and to live independently. Little consideration is given to slow and sustained improvements, so rehabilitation programs are not being considered.

"I had been moved to aged care after I went into hospital because I fractured my leg in three places. It had been 5 months, in hospital...It got to the point where they said that they had kept me in the hospital for as long as they could and so said I'm sorry but you have to go. No facility would take me without a pension so I had to get a pension. The facilities wouldn't take me without a steady income. So, I went through a month of applying for pensions. It was not easy; it was hard to find and to get through it..."

Anna Freeland* - 61 years old

²² Barry, S., Knox, L., Douglas, J. (2019) Time's Up: The Experience of Entering Residential Aged Care for Young People with Acquired Neurological Disorders and Their Families. *Brain Impairment*. Vol 20, Issue 1. pp37-48.

NO KNOWLEDGE

'No knowledge' is characterised by not having enough knowledge around health, disability, aged care and social support systems to make a well-considered decision. Young people in this situation rely on the expertise and advice of health professionals to guide them through the process. Yet, there are a number of issues around the provision and processing of information.

Acquiring information is difficult and is described as "trying to find your way around an intricate maze". The delivery of information from health professionals to young people and their families was ad hoc and incomplete, further complicated by not having enough time to undertake their own research, in order to make an informed decision. The heightened emotions and enormous stress resulting from the situation meant that processing information was difficult.

Families trust health professionals to provide an informed and comprehensive explanation of the different options available, yet this is not necessarily the case. Some felt that there was a resistance among health staff to exploring options beyond aged care.

"I was assaulted by my boyfriend when I was 16 and ended up in a nursing home. There was nowhere else for me.

"The doctors gave me an incorrect diagnosis, and told my parents that I would be nothing more than a vegetable my whole life.

"Because of that, none of the rehabilitation facilities were prepared to take me. Doctors should listen to and be guided by parents. Obviously, they know their children. My parents could see that I was comprehending everything that was going on and blinking for yes and staring for no. The doctors didn't believe them or me.

"If they had have listened to my parents who told them I was a strong and determined young girl, they would have given me the appropriate rehabilitation."

Anj Barker – 33 years old

NO CHOICE

Having 'no choice' translated to people feeling that there were few options outside aged care offered for consideration. The decision to go into aged care is underscored by this lack of viable alternatives.

Having more time for rehabilitation is not an option on offer, and being denied rehabilitation all together due to the narrow admission criteria that governs access is common. Options for follow up or reassessment for rehabilitation are limited.

"I was admitted to hospital in 2011. After 2 years there I was moved to aged care where I lived for 4 and a half years.

"I was standing and doing physiotherapy at the hospital, but when I moved to the nursing home, I was put into a wheelchair. I had never lived like that before, I had to learn everything new. If I had been transferred into a rehabilitation facility, it would have been very different for me.

"With no assistance from the system, and no rehabilitation in the aged care facility, I was told that I was there to die."

"When they told me I was going into a nursing home, I was in tears, I didn't want to go, but I knew I'd be out on the streets if I didn't. I didn't go willingly, but I did go."

Lisa Jackson - 56 years old

"Basically, I had to go to [the nursing home] because they couldn't do the personal care I required at home without modifications to my home, but they couldn't make the home modifications because it was a private rental.

"I couldn't get housing assistance to get into a home that could be modified to suit me. Suitable housing commission places are few and far between."

"We had three teenagers at home when we first started looking for a house, but we only said two kids to improve our options. Ideally, we needed 3 or 4 bedrooms (3 bedrooms with a garage would've been okay; I could've kept equipment like the hoist in the garage). But getting accommodation for someone who's not a single person is really hard. Everything was like a 2-bedroom unit suitable for retirees. We went and had a look at a couple of 2-bedroom places that became available but there was nothing really suitable.

"The Department of Housing offered us two brand new 2-bedroom units next to each other, but you'd still have to pay two gas bills, two hydro bills, two insurances etc. So, if you get your pension on one hydro bill, it wouldn't cover both. They couldn't bill them together."

Peter French* - 47 years old

Solutions

The use of independent advocates for young people and their families experiencing a health crisis is supported by the research findings. The lack of knowledge around the intersection of health, disability and aged care, the ad hoc provision of information from professional staff, combined with the considerable distress associated with a crisis situation would be alleviated by an advocate.

The use of independent advocates would address the significant gaps in the provision of emotional and practical support, and ensure appropriate information is provided.

Providing comprehensive, accurate and complete written information around RAC entry (including case studies of people who have avoided RAC) will support young people and their families to make informed decisions around the transition out of the health setting, and longer-term living arrangements. Information around availability and eligibility for rehabilitation provided in a written format should also be provided.

Individualised and extended rehabilitation programs would give young people the time to get to a point where RAC is not the only alternative. Policy responses that address the rehabilitation needs of people with complex support needs would ensure that aged care does not remain the default solution for young people facing possible admission to RAC.

KEY POINTS:

- People commonly enter RAC from hospital, rehabilitation or after eviction from a group home
- The experience of the pathway to RAC is punctuated by three themes: no time, no knowledge and no choice
- The use of independent advocates would assist people to better navigate the complex interface between the NDIS and health sector
- Extended rehab programs would give people the opportunity and time to get to a point where RAC is not the only option

6

PATHWAYS IN:

Problems with the health/NDIS interface and hospital discharge and how we can address them

This chapter closely examines the systemic issues that all contribute to young people being forced to live in aged care. It looks closely at the problems that arise when the health sector, disability sector and aged care sector intersect with the NDIS. This chapter illuminates the problems that staff in these sectors face while trying to navigate the complexities of the health/NDIS interface and hospital discharge.

1. HEALTH SYSTEMS LACK KNOWLEDGE OF THE NDIS PATHWAYS AND PROCESSES

Health practitioners are largely unfamiliar with the NDIS, its principles, operations and procedures. Health treating teams lack experienced staff to work with patients through the stages of the NDIS pathway.

In a survey by the Summer Foundation, of 93 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. Nearly three quarters of the survey group (72%) rated their confidence in how to identify and utilise opportunities under the NDIS for their clients as poor or fair.²³

Current hospital discharge teams struggle with the complexities of the NDIS. They report that they require additional staff resources to meet NDIS system demands. As one clinician said: *OTs and social workers end up being care coordinators, therapy providers and planners. It's overwhelming, and a huge amount of time for everyone.*

Health workers' inadequate knowledge of the NDIS system has resulted in their use of 'trial and error' practices rather than informed and documented procedures. Where health workers do not have sufficient competency in NDIS terminology, their recommendations have been less likely to be approved in participant plans. Inadequate knowledge and a lack of hospital resources has also led to health workers unnecessarily completing two different discharge processes, for hospital and the NDIS, resulting in additional work pressures on staff.

23 Nous Group, (2018). *Evaluation of the Increasing Capacity of the Health and Aged Care systems program – Formative Report*. Summer Foundation (unpublished).

"The level of understanding my team have of the NDIS is very low. That has to do with the fact that the NDIS is still new for everyone, we're all learning."

Rosie Moubarak, ACAT & RAS Team Leader SWSLND

Solutions

Improving skills and knowledge of health providers is critical to ensuring that they are competent to facilitate smooth and efficient pathways from hospital admission to discharge, with NDIS plans in place and supports activated. Strategies to build capacity include:

- Training for health providers on issues such as disability awareness and supports for people with complex needs; on NDIS principles, processes and terminology, and the use of tools such as Rapid Response processes for practitioners
- Opportunities for collaboration and peer support through discharge communities of practice around Australia to share expertise and resources
- Development of assessment protocols so people with complex disability support needs can be quickly identified and responded to, and the establishment of procedures for early escalation of supports
- Building collaborative relationships between health and the NDIS, and with primary care, housing providers and all other stakeholders so a seamless transition pathway can be achieved, with the ultimate goal of discharging in to the community
- Implementing the NDIA Complex Pathway should give all NDIS participants in aged care, or hospital settings and at risk of entering aged care, access to significant supports. Complex Pathway planners and support coordinators should provide better and more information and enhance capacity building for YPIRAC

2. GAPS EXIST IN KNOWLEDGE AND EXPERTISE OF DISABILITY

Health systems have historically lacked the time and expertise to support people with complex support needs in the hospital setting, and to find out how their needs might be met under the NDIS. Many have not been exposed to general disability awareness education or information on the responsibility that mainstream health systems now have to be accessible to people with disability.

In a hospital setting, staff may see only a narrow perspective of the life of a person with disability. The medical perspective narrows the attention on the person's immediate treatment requirements in a specialised and artificial environment. It is difficult for staff to see people with disability as living a life in the community, and to grasp what is possible now, in enhancing their choice and control under the NDIS.

"To be told by professionals along the way and medical experts, she will never recover, find a nursing home that's willing to take her as a 29-year-old. I literally brought my sister home and taught myself how to do it..."

"It is a serious gap, that pathway from healthcare over to NDIS needs a lot of work. It was just this revolving door and there's something missing there."

Toni Rowe, sister of young woman with an ABI

"In rehab hospital, Geoff [son] was denied access to any hydrotherapy (which has evidence to be incredibly effective), he was denied any independent living rehabilitation such as cooking and denied any access to power wheelchairs because he was 'too dangerous to himself'. He now cooks, is in both manual and power wheelchairs and can do many things for himself.

"By the end of the first year it seemed clear that rehab hospital had determined that Geoff had no worthwhile use to society having denied him significant rehabilitation paths that should have been open."

Mark Toomey, fought for his son Geoff (aged 39) to stay out of aged care

Solutions

Capacity-building through training and peer support is necessary to increase general awareness of health services staff, both of disability and of the responsibility of mainstream services and institutions.

The Summer Foundation has identified NDIS 'champions' in ACATs who have worked beyond their current roles. They have pushed back on hospital discharge staff referring younger people to ACAT assessment before they have explored other housing options, have submitted an NDIS request, and have an approved plan. This should be common practice.

3. NDIS PROCESSES ARE DELAYING HOSPITAL DISCHARGE

The introduction of the NDIS is a very significant change to the way health services support people with disability to leave hospital. The introduction of such a rapid and major reform requires hospitals and the NDIA to quickly develop new ways of working.

Four issues illustrate how the introduction of the NDIS is leading to longer timelines for hospitals to support people to be discharged:

Health clinicians face difficulties in deciding when to activate Access Request Forms (ARF). This 'point in time' step is difficult to synchronise with the clinical processes of determining when a person has permanent and lifelong disability. Health practitioners therefore can find it difficult to make early submission of ARFs – despite NDIA advice that this is an important strategy to allow the NDIA to respond in a timely way.

Current hospital discharge expertise is inadequate in an NDIS planning context. In the past, health has planned only for immediate discharge needs after addressing acute and sub-acute needs. Now with the NDIS, discharge planners need to incorporate expertise on planning for life-long disability. During a professional development training session, one of the clinicians stated: *We used to be planning for a period soon after discharge, now we are trying to predict their need 12 months down the track.*

Health providers require processes for a rapid NDIS response to address sudden changes in circumstances or health needs. Timely responses are needed to avoid future readmission. The NDIS is not structured to deploy resources quickly, in response to changing patient needs. Participants with high and complex support needs can experience unanticipated events, for example for urgent equipment upgrades or repairs. There is often no funding to cover emergencies if not already identified in a participant's plan.

There is a lack of central coordination across departments. With state disability protocols disappearing through the transition to the NDIS, access to expertise in disability housing and accommodation for people with disability and complex care needs is diminishing. Increasingly, health practitioners have been required to fill this gap as state-based resources and expertise disappears.

"I thought by going back into hospital that I'd be able to be discharged back into the community now that I had my package. But the NDIS told me that they couldn't generate my plan and package while I was still in hospital. The NDIS needs to start to work with the hospitals."

Chris Bennett* - aged in 40s

"Health services need to have NDIS experts working within the teams that are supporting patients to leave hospital with NDIS plans. People who are tasked with staying up to date with the NDIS and having their fingers on the pulse, because it is constantly changing and evolving."

Brynn Lewin, OT Austin Health

4. TIMING AND URGENCY DIFFERENCES BETWEEN NDIS AND HEALTH

Timeframes for NDIS access and planning have become a major hurdle. Patients with disability in hospital or rehabilitation can experience long waits of 12 weeks or more for completion of engagement, planning and plan implementation. For a group of 13 patients with complex needs, QLD Audit Office documented an average length of time to have reasonable and necessary supports in place for safe discharge of 172 days.²⁴

Current NDIA timeframes for access (21 days), planning (no timeframes) and reviews (taking up to 9 months) do not align with the rapid responses that are required for the target cohort – those with high and complex support needs.

In addition, health workers have not been able to rely on timelines (set by the NDIA) being met by NDIS planners. Consequently, they have been unable to predict how long each NDIS stage will take, and synchronise expected outcomes with hospital discharge goals. One health practitioner commented: *Reasonable wait times are defined differently by the health sector and the NDIS*. For the people with complex support needs it has meant remaining in health settings, where their disability support needs are not being met, and specialist disability supports are not delivered.

Many people with complex disability needs require NDIS resources to assist them early in their hospital stay. Essential knowledge and information about the NDIS that they require as part of their pre-planning stage may not be available. Where they do not already have a plan in place, support coordination is not available until their plan has been approved. They need the services of support coordinators early to navigate the interface between hospital and the NDIS, particularly if they do not have advocates, and/or have limited capacity to advocate for themselves.

There have been increasing delays in NDIS approvals for home modifications, assistive technology and specialist supports, which make it difficult to discharge participants. The result is longer stays in acute and/or sub-acute beds, causing increased pressure from local health networks, as they cannot release those beds to meet their incoming demand. These delays often result in young people being admitted into RAC.

NDIS planning processes can be slow and difficult for participants to navigate. They are caught in delays when their NDIS plan is activated too late to prevent discharge without supports in place. It can be difficult to access support coordinators early enough to assist people with complex needs to work through the disjointed steps and navigate pathway requirements. Participants report being stressed, apprehensive about the future, and less willing to request changes.

²⁴ The National Disability Insurance Scheme Report 14:2017-18 Queensland Audit Office 2018

"I didn't notice any difference being discharged from hospital with my NDIS plan. It was just like before. I think if the NDIS were involved it would be more streamlined. I'd be able to access services and support hours straight away. It could be all organised at once instead of leaving the hospital and waiting for a plan review to try to add services to my plan. If I had these things when I was discharged I would get better faster instead feeling like I'm going backward about 50 steps."

Lucy Stephens* - 35 years old

Solutions

The problems evident in the mismatch of NDIS processes and hospital discharge procedures and their differences in timing and urgency responses can be overcome by the following measures.

A 'fast track' system for people with complex needs in hospital would enable them to have their NDIS access request processed rapidly, and reduce the time for their planning to start. Building in a capacity for hospitals to develop a draft NDIS plan to be reviewed by NDIS specialists would be effective in addressing urgent planning requests, such as for equipment repairs.

Hospital discharge processes would be enhanced by access to specialist NDIA planners. These specialist planners would improve the capacity for rapid NDIS response processes through the NDIS planning pathways.

Lack of central coordination across departments can be addressed by ongoing collaborative processes between health and the NDIS on joint escalation procedures. Better coordination would also be achieved by the establishment of an NDIS/health interface advisory group of community stakeholders.

The Summer Foundation has developed a Collaborative Discharge Approach (CDA) for health services and the NDIS to provide an integrated process from hospital admission to discharge. (See Chapter 7 for more details).

Support for navigating and coordinating hospital procedures and NDIS processes requires early access to support coordination through short-term plans. Health providers also can build their capacity to ensure that they make accessible education and information materials available for people to inform their NDIS pre-planning.

The 'Getting Ready for NDIS planning' Toolkit published by the Summer Foundation has been written for health practitioners to deliver this information to their patients. The suite of training modules is designed to support hospital staff so they can learn how to work well with the NDIS and to understand their roles.

5. NDIS PLANNERS AND SUPPORT COORDINATORS LACK CLINICAL EXPERTISE

NDIS planning processes place NDIA planners at the centre of decision-making around the supports a person with disability is funded for in their plan. By establishing processes where planners are required to make a determination about every individual support in a participant's plan, they have become involved in making decisions about funding supports that are integral to the health and wellbeing of people with disability.

There is an argument that it is advantageous for planners to have no clinical expertise, as they should not be part of clinical decisions. However, as the NDIA has inserted planners so far into the prescriptive role, they are now responsible for 'reasonable and necessary' calls on every support. Their decisions influence whether clinical decisions are implemented.

Health worker recommendations for necessary supports are not always translated into participants' plans. NDIS planners can lack detailed knowledge of the health system and have an inadequate understanding of participants with complex health and disability support needs. Without appropriate training in the use of clinical expertise, planners can fail to incorporate key support recommendations that enable people to live an ordinary life in their community.

Participants face service gaps when recommendations for supports that are related to their functional impairment, and require nursing and allied health workers to deliver, are not included in their plans.

Solutions

Training for specialist NDIS planners, on clinical support requirements of people with complex disability and health needs, would address the problems caused when supports based on clinical recommendations are not approved in plans. Capacity building for specialist planners in clinical expertise would be facilitated by their location in acute and sub-acute hospital settings.

6. NEW GAPS IN SERVICES HAVE EMERGED

Prior to the NDIS, state disability services developed tailored responses based on identified gaps in the health system such as the *Slow to Recover* program in Victoria for people with acquired brain injuries, and the *Spinal Cord Injury Response Service* in QLD.²⁵ Services de-funded include: catheter care, wound care, occupational therapy assessments of home modifications, and meal time management plans. Such programs are no longer available as they are not funded under the NDIS framework. At the same time, they are not being replaced by the health system. This means that functional gains that can lead to increased independence and quality of life are being forfeited, leading to higher downstream costs for both systems.

More gaps are emerging in previously state-funded information and advocacy services. This has resulted in health practitioners not being able to access expertise in disability housing. Health practitioners do not have the expertise to fill this gap, and report that a lack of accessible housing is the most common cause of delayed hospital discharge.

In many jurisdictions the loss of community nursing means that people with complex needs can no longer access these critical supports in the community. The Disability Reform Council's decisions on 28 June 2019 will make a significant contribution to closing these gaps.

Health practitioners are prevented from responding effectively in the NDIS domain by confusion in the application of the COAG Principles²⁶. While these principles contain details of the respective roles of the NDIS and health, clinicians report that they are being interpreted in different ways. One health worker said: *COAG Principles are extremely useful, but I have had the NDIA say "they're just principles and we have interpreted them differently to you"*.

NDIS planners and regional staff are not clear about the roles and responsibilities of the NDIS for the continuation of funded supports to participants. Although the COAG Principles define the responsibility of the NDIS to provide supports in hospital where the participant has complex communication needs or challenging behaviours, these terms require interpretation when applied to particular situations.

Solutions

A national data collection and reporting framework is required to keep track of people with complex needs in the health system. This data should be used to investigate the gaps in services arising from changes in roles and responsibilities of Commonwealth and state jurisdictions. The framework would enable reporting on the length of hospital stays beyond discharge date for people with complex needs, and on the outcomes of post-discharge follow up. The national data collection and reporting framework must incorporate a feedback loop to address deterioration in participants' health and wellbeing.

²⁵ *The National Disability Insurance Scheme Report 14:2017-18* Queensland Audit Office 2018

²⁶ *Principles to Determine the Responsibilities of the NDIS and other Service Systems* COAG 2015

Government funding is also needed to investigate and resolve service gaps that are identified.

Health services and the NDIA have a joint responsibility to review and clarify COAG Principles, roles and responsibilities in the context of identification of gaps in services and lack of agreement on interpretation of their application.

Clarification of the COAG Principles and operational interpretations being undertaken by the Disability Reform Council, has not been concluded.

Update: On 28 June 2019, COAG decided that the NDIS will fund disability-related health supports where the supports result from the NDIS participant's disability and are a regular part of their daily life. Some examples include respiratory and continence supports, supports to manage epilepsy, pressure wounds, swallowing difficulties, and podiatry.

7. COMMUNICATION BETWEEN HEALTH AND THE NDIS NEEDS TO BE STREAMLINED

Health workers have been unable to access NDIS contact details consistently. Health workers have spent considerable amounts of time trying to get information and advice from the Contact Centre, and following up issues on behalf of patients from the right person at the NDIA.

In addition, health clinicians have been unable to access NDIS planners prior to planning meetings, during plan reviews and in the post plan approval phase. Discontinuity of NDIS planners and support coordinators due to staff turnover interferes with health practitioners' ability to discuss individual participants effectively, and progress positive discharge outcomes for participants with complex support needs.

Solutions

Locating specialist NDIS planners in hospital settings and enabling early access to support coordination will streamline communication between health and the NDIS, and reduce the need for access through the Contact Centre.

KEY POINTS:

- The health sector lacks knowledge around complex disability, NDIS pathways and processes
- NDIS planners and support coordinators lack clinical expertise
- NDIS processes are delaying hospital discharge because the health system and the NDIS have a different view of timing and urgency
- NDIS resources are activated too late to support participants, with more "pre-planning" supports needed to be accessed by participants prior to a formal NDIS planning decision
- Communication between health and the NDIS needs to be streamlined
- Education campaigns and capacity building exercises are required to address knowledge gaps across all levels of health and the NDIS



AGED CARE AND THE NDIS: A CASE FOR SEPARATION

In 2011, the Productivity Commission concluded that the state-based disability system was:

'underfunded, unfair, fragmented, and inefficient, and gives people with a disability little choice and no certainty of access to appropriate supports. The stresses on the system are growing, with rising costs for all governments.'²⁷

For decades the residential aged care sector has been providing accommodation and care to people under 65 whose needs could not be met by their state-based disability service system.

The Productivity Commission developed the blueprint for the NDIS. Making the case that:

'People would have much more choice in the proposed NDIS. Their support packages would be tailored to their individual needs. People could choose their own provider(s), ask an intermediary to assemble the best package on their behalf, cash out their funding allocation and direct the funding to areas of need (with appropriate probity controls and support), or choose a combination of these options.'²⁸

As we approach full rollout it's imperative to disaggregate the responsibilities of the aged care sector and the responsibilities of the NDIS. However, early signs are that the two systems are tightly intertwined and that work needs to be undertaken to separate them.

The market for NDIS providers is immature and particularly thin in regional, rural and remote areas. Aged care by contrast is a relatively mature sector, with RACs located across the country. Return on investment on RAC beds are highly variable, with only 68% of RAC providers reporting a net profit in 2016-17.²⁹ RAC providers are already considering ways to expand their income streams by tailoring their service offering to meet demand amongst NDIS participants residing in their facilities. Indeed these 'enhancements' may also be used to market their facilities to prospective residents.

²⁷ Productivity Commission 2011, *Disability Care and Support*, Report no. 54, Canberra. P 5

²⁸ Productivity Commission 2011, *Disability Care and Support*, Report no. 54, Canberra. P 3

²⁹ 2018, Aged Care Financing Authority (ACFA), *Annual Report on the Finding and Financing of The Aged Care Sector* <https://agedcare.health.gov.au/reform/aged-care-financing-authority/2018-acfa-annual-report-on-funding-and-financing-of-the-aged-care-sector> p133, [Accessed 27 May 2019]

In October 2017, the NDIA began to include the following funding line items into the plans of younger people in RAC:

41. Assistance With Daily Life Tasks In A Group Or Shared Living Arrangement 01_049_0115_1.1. Cross Billing Payments For Residential Aged Care Subsidies And Supplements (This payment appears in the plans of YPIRAC where aged care is considered a reasonable and necessary (R & N) support).
42. Assistance With Daily Life Tasks In A Group Or Shared Living Arrangement 01_050_0115_1.1. Assistance With Daily Life Tasks Provided In Residential Aged Care Facility. This payment refunds NDIS participants their means tested care fees and accommodation payments/contributions, paid as a daily amount up to certain caps.
665. Management Of Funding For Supports In Participant's Plan 14_032_0127_8.3. Financial And Service Intermediary - Set Up Costs. The setting up of the financial and service management arrangements to assist with the managing of funding of supports.

The inclusion of NDIS funding for a financial intermediary, and designating that the other 2 supports are Plan Managed, allows the participant to purchase supports from an aged care provider who is not registered to provide NDIS supports. As the NDIS matures, and aged care providers have more exposure to the scheme and the funding available, many providers are looking into how they can expand their service offerings to include a range of supports to NDIS participants in their facility, or as a way to market their services to NDIS participants.

Part 1 of this chapter highlights action that is needed to separate disability and aged care supports to ensure the integrity of the NDIS for participants; upholding their right to individually tailored supports, choice and control over their providers and the separation of housing and support.

Part 2 of this chapter argues for changes to the Aged Care Act 1997 to support the separation of the aged care sector from the disability sector.

PART 1: SEPARATING THE NDIS AND THE AGED CARE SECTOR

➔ **PROBLEM: AGED CARE MARKET EXPANSION THREATENS THE SAFEGUARDS OF THE NDIS**

The separation of housing and support is one of the fundamental changes at the heart of the NDIS. From a public policy perspective, the *SDA Rules 2016* marks the end of an era of institutionalisation for people with disabilities. For individuals, these rules, together with the *NDIS Quality and Safety Framework*, enshrine an important range of protections including portability of supports, separation of housing and support, choice of service providers and control over the delivery of purchased supports.

Working with a range of providers is a foundational building block of enshrining choice and control for participants. It is important to note the NDIS Quality and Safeguards become more stringent as the level of vulnerability of the participant and support being delivered increases, including protecting participants from providers with a conflict of interest.

There is both a real and perceived conflict of interest where aged care providers develop and deliver service offerings for NDIS participants living in their facilities. Individuals who purchase supports such as community participation, allied health etc from their aged care provider, are forgoing capacity building opportunities afforded by leaving the facility to attend appointments in age-appropriate mainstream community settings.

The Specialist Disability Accommodation module of the National Disability Insurance Scheme (Quality Indicators) Guidelines 2018³⁰, which is an instrument made under subsection 181D(2) of the *National Disability Insurance Scheme Act 2013*, provides guidance on the particular vulnerability of people with either an extreme functional impairment or very high support needs, who are eligible for SDA support, and provide a relevant framework to consider the conflict of interest for aged care providers. (See Attachment 1 for excerpts of the Guidelines).

Clearly RAC differs in many fundamental ways from SDA, most notably, the limit of 5 residents per SDA dwelling and the requirement that the SDA provider and the supported independent living (SIL) provider are separate entities. However, the case for applying the most stringent safeguards to participants in the most vulnerable circumstances (younger people living in RAC), deserves consideration. In effect, RAC providers are supplying both accommodation and 'supported independent living' (SIL) supports to individuals living in their facilities. These individuals are without the protection of the NDIS SDA Quality and Safeguards that protect the needs and interests of SDA tenants. YPIRAC depend primarily on the quality and safeguard regulations under the *Aged Care Act 1997* for their protections. The Aged Care Regulations are designed to protect the frail aged at the end of their lives, not to build the capacity of people with disability to re-engage in the social and economic life of their community.

There is widespread confusion about the Quality and Safety frameworks that apply for NDIS participants in RAC. The Summer Foundation's extensive consultations with RAC providers indicates that they believe that, as they are not required to register as NDIS providers to provide the NDIS items listed above, they are therefore, not bound by the *NDIS Quality and Safety framework* or *Code of Conduct*.

It is our understanding that both the quality and safeguards under the *Aged Care Act 1997*, and the NDIS Code of Conduct apply when delivering listed NDIS items i.e. the bed and 'hotel' style supports. For individuals purchasing supports, seeking protections under multiple legislative instruments and administered by different commissions will be confusing at best, and disempowering at worst.

The National Disability Insurance Scheme Code of Conduct³¹ is set out in the *National Disability Insurance Scheme (Code of Conduct) Rules 2018*. As discussed, RAC providers are not required to register as NDIS providers to provide the specified NDIS items. They are however, bound by the NDIS Code of Conduct:

The Code of Conduct applies to:

- Registered NDIS providers
- Unregistered NDIS providers
- Providers delivering information, linkages, and capacity building activities
- Providers delivering Commonwealth Continuity of Support Programme services for people over the age of 65

(Attachment 2 sets out the NDIS Code of Conduct.)

30 National Disability Insurance Scheme (Quality Indicators) Guidelines 2018, <https://www.legislation.gov.au/Details/F2018N00041>

31 NDIS Quality and Safeguards Commission, March 2019, The NDIS Code of Conduct, Guidance for NDIS providers

➔ SOLUTION:

The NDIS Quality and Safety Commission must establish a division with particular expertise relating to NDIS participants living in, or at risk of admission to RAC. The division could have 2 areas of focus:

Firstly, educating the aged care sector generally, and RAC providers in particular, on their obligations under the *NDIS Code of Conduct* is required. Aged care providers also need higher level policy advice relating to developing services to cater to NDIS participants. For example, creating wings, wards or facilities specifically for NDIS participants, is in breach of the intention of *NDIS Act 2013*, and its enshrining of Australia's obligations under the UN Convention on the Rights of Persons with Disabilities.

Education and the provision of information should be backed by the imposition of severe penalties and sanctions for RAC providers who disregard the requirement to manage real or perceived conflicts of interests, and/or engage in 'sharp practices' as defined under the *NDIS Code of Conduct* (See Attachment 2).

Secondly, an education campaign designed for NDIS participants who are living in RAC, or at risk of admission to RAC, and their informal and formal supporters. This campaign should educate this cohort about their rights and the importance of exercising choice and control when purchasing NDIS funded supports, and the capacity-building opportunities of contracting community-based providers.

➔ PROBLEM: RAC DOES NOT OFFER APPROPRIATE SUPPORTS

"I am disabled but I still want the same things non-disabled people do, somewhere friends and family can come and stay/visit and to have friends in the community. I did not change my personality or my intellect as a result of my disability and I struggle with the way the NDIS suggests that I need to learn living skills to reduce my dependence on support. I have MCS and ME/CFS, two organic diseases that result in low physical functional capacity and an inability to generate energy on demand. After listening to severely affected dementia patients crying out in pain for months on end, I think it's important to re-examine the way medications are managed to ease people's suffering even at the expense of shortening their lives. We need to enable and encourage home visits by GPs/ doctors. There needs to be minimum staffing ratios for both nurses and carers to ensure all care needs are met in a non-competitive way. Unannounced spot checks by accreditors, need to be held on weekends as well as weekdays, otherwise staff are not replaced by agency staff on weekends."

Janice Edwards* - 35 years old, in RAC for 6 years

As Janice Edwards* describes, many younger people are admitted to RAC to have access to 24-hour care including nursing care, only to find that there are long wait times for assistance with personal care, and that nursing care may not always be available on-site.

➔ SOLUTION:

The NDIS needs to provide sufficient funding for support coordination and plan management to ensure that YPIRAC have adequate means to purchase supports from a range of providers that are not available in their facility.

➔ PROBLEM: RAC IS NOT AN APPROPRIATE PROVIDER OF PALLIATIVE CARE FOR YOUNGER PEOPLE

Residential aged care is designed to provide end-of-life care to the frail aged. Around 450 younger people die in RAC each year without access to quality community palliative care services.

"He shut down the moment he entered the nursing home. He never left his room the whole 5 weeks he was there."

"I had to keep working during this time, so I visited him every night after work and each weekend over the time he was there. He went into the nursing home as respite and I was being pressured by the nursing home to make him permanent. When he was close to dying, I worked that out myself by seeing a record of his vital signs and looking up what that meant. It would've been nice to be guided through this phase before he died. We didn't have assistance in making choices."

Jessica Dodds, wife of younger man with cancer who died 5 weeks after entering aged care

➔ SOLUTION:

Younger people in RAC need access to quality palliative care services to assist them to come to terms with their premature death, define what a good death means to them, and support them to work towards it.

PART 2: THE AGED CARE ACT

Part 2 of this chapter argues for changes to the *Aged Care Act 1997* to support the disaggregation of aged care and disability systems to protect the rights and dignity of younger people with complex disability. We identify 2 sets of problems and solutions, recognising that the market for disability services is still developing:

- A first round of changes to address problems with the Act that can be mitigated or removed by immediate action.
- A second round of solutions can be implemented in 2025. By this time, the NDIS implementation will be complete, and the NDIS and the market should have reached maturity and be operating effectively to meet the needs of people with high and complex needs.

Immediate Reforms to the Aged Care Act

➔ PROBLEM: INEFFECTIVE DIVERSION FROM AGED CARE PATHWAY TO NDIS PATHWAY

There are insufficient stopgaps in place to divert younger people away from aged care. The *Aged Care Act 1997* delegates authority to approve a person for a Commonwealth subsidised aged care place to Aged Care Assessment Teams (ACAT). ACAT make approvals in accordance with the Approval of Care Recipients Principles 2014 made under the Act. The *Aged Care Assessment Supplementary Guidelines for Younger People with Disability* 2017 operationalise the COAG Principles and provide additional guidance for ACAT assessors on how to process a request to undertake an assessment of a person under 65 years of age. They include a hurdle requirement that: '...all disability service options have been exhausted and there are no other services more appropriate to meet the person's needs available'.

The Guidelines are under review, therefore, there are currently no 'hurdles' in place to divert younger people away from the aged care sector. This is important because it's relatively easy for a younger person with urgent complex disability needs, who is not an NDIS participant, to enter the aged care system, compared with becoming an NDIS participant. This also applies if the person is already an NDIS participant whose support needs increase. They must use the NDIS Change of Circumstance form to get a revised plan that allows them to remain living in the community, or to be discharged from hospital back into the community. This may take too long for their needs to be met if intensive supports are required.

In addition, individuals can circumvent ACAT and purchase RAC services directly from a provider. There is the potential for NDIS participants to use their core funding to purchase a RAC bed which subverts the intention of the scheme.

"The aged care assessment was rushed and done in 20 minutes the following day. She had my future in her hands, and with a few clicks on her tablet, she'd relegated me to aged care. The whole process was cold and impersonal. "

Chris Bennett* - aged in 40s

➔ SOLUTION:

Guidance to ACAT assessors on how to assess people under 65 must be set out in the *Approval of Care Recipients Principles 2014*, made under the *Aged Care Act 1997*. These principles must make it explicit that under the *NDIS Act 2013*, the NDIS has responsibility for providing reasonable and necessary supports to people aged under 65 years, to live in the community.

➔ PROBLEM: ACATS MAKE NDIS DECISIONS, WITHOUT NDIA INVOLVEMENT

An apparent anomaly occurs when an ACAT provides approval for an aged care place for an NDIS participant. It is therefore making a funding decision on behalf of the NDIA, as the NDIS has agreed to provide funding for the care places (and certain means-tested fees), in NDIS participants' plans. However, under the *NDIS Act 2013*, only people with the delegated authority of the CEO of the NDIA can approve funding for NDIS participants. For young people in aged care, this is a problem because there may have been additional funding that the NDIA could have provided to assist the person avoid aged care. However, because the aged care placement decision does not include the NDIA, these additional opportunities may not be considered.

➔ SOLUTION:

People under 65 years who meet the NDIS requirements need aged care funding approved by the NDIS prior to assessment by ACAT.

➔ PROBLEM: RAC IS NOT SET UP TO ENABLE CAPACITY BUILDING

RAC is a disabling environment. Many younger people residing in RAC may not be equipped to exit RAC and return to live in the community without significant capacity building, person-to-person and capital supports in place. Sourcing, establishing and transitioning into sustainable housing and support in the community may require short stays away from RAC, of increasing duration over many months. Many YPIRAC may not have the confidence to work towards exiting RAC if they think it will jeopardise their current aged care arrangements. Under section 42-2 of the *Aged Care Act 1997*, Leave from residential care services, residents are only entitled to 52 nights of social leave per year. After 52 nights the Commonwealth payments to the aged care provider cease and providers may regard the bed as vacant.

"When I went into aged care I wanted to do some physio and speech therapy but nobody would help me. I wanted to exercise and do some rehabilitation to improve myself. I was given no encouragement at all to help myself.

"They told me they were there for old people and not for rehabilitation."

Belinda Maxwell* - aged in 50s

"In the nursing home where I'm living, only once have I been asked to go out and it was me and another guy and we got taken down to something like a senior citizen club and that was the only place I've been to where they called me a taxi. There is a vehicle at the nursing home to take people out but unfortunately if you're in a wheelchair you don't go. Makes me feel like if you're in a wheelchair you're not welcome."

Lachlan Davies* - aged in 50s

➔ SOLUTION:

Doubling the approved social leave period for younger people would enable YPIRAC to access resources and build their confidence and skills to plan for their future. Furthermore, funded supports for personal assistance, community access, transport and allied health are important for YPIRAC to build their capacity to exit aged care.

➔ **PROBLEM: LIMITED DATA AROUND YPIRAC CIRCUMSTANCES AND OUTCOMES**

Strict provisions in the *Aged Care Act 1997* protecting the privacy of RAC residents' personal information makes it difficult for the NDIA and advocacy organisations to understand changing YPIRAC cohort circumstances and outcomes. There is a vital need for data on the continued utilisation of RAC in rural and remote areas, particularly by members of Aboriginal and Torres Strait Islander communities.

There may be people under 65 in RAC who don't meet the NDIS eligibility requirements because they are refugees, or are working in Australia on temporary migration visas. They may continue to rely on RAC as a safety net provider. The number of YPIRAC in this group is not currently published.

Tracking the NDIA's progress towards the targets set out in the National Action Plan while changing embedded practices in the aged care and disability sectors that allow people under 65 to be admitted to RAC will require the gathering and publication of quality de-identified individual and cohort data.

➔ **SOLUTION:**

To ensure accurate data on younger people in RAC is available to interested parties, the 2 annual reports required to be tabled to Parliament under the *Aged Care Act 1997*, (Report on the Operation of the Aged Care Act, and Report on the Funding and Financing of Aged Care Sector), should each be required to include a chapter on the number and circumstances of people under 65 permanently admitted to RAC. The reports should address:

- Those deemed ineligible for the NDIS as current RAC residents
- Those who are deemed eligible but aren't moving out
- Those who don't meet NDIS residency eligibility requirements but still get admitted

➔ **PROBLEM: EMERGENCY RESPITE IN RAC LEADS TO PERMANENT ADMISSIONS**

When a person's usual care arrangements breakdown they can use emergency respite in a RAC facility for up to 5 days without an ACAT assessment. During this time the RAC provider should request an ACAT assessment to ensure Commonwealth funding is provided to cover the cost of providing an aged care place. It's important that emergency respite does not become a pathway for NDIS participants to be admitted to RAC as it bypasses the application of a variety of safeguards recommended in this section.

➔ **SOLUTION:**

Allowing ACAT assessors to approve an emergency respite period of 63 days would allow enough time to access the NDIS as soon as possible, if they are not already participants. The ACAT assessor needs to facilitate an urgent access request on behalf of non-participants if they consent. If the person is already an NDIS participant the assessor must facilitate an immediate review of their NDIS plan on the basis of a Change of Circumstances if the participant agrees.

Reforms to the Aged Care Act from 2025

➔ **PROBLEM: RAC IS BEING USED AS A PROVIDER OF CARE, ACCOMMODATION, RESPITE AND REHABILITATION TO PEOPLE UNDER 65 YEARS**

If we are to resolve the issue of young people in RAC, we need to dismantle the pathways that lead to permanent admission. This means that in the longer term, RAC should no longer be a respite or rehabilitation solution for young people. We recognise that there are challenges in removing the option of aged care as a provider for young people with complex needs, particularly in rural and remote areas. The challenges of thin markets as well as issues related to indigeneity and CALD identity will need to be taken into account. Extensive stakeholder consultation will be needed before action is taken. However, we believe that with a fully functioning NDIS the problems can be addressed.

"I desperately wanted to walk and talk again. Because of my ventilation, I had to live in a nursing home to get rehabilitation."

Hannah Jacobs* - aged in 30s

➔ **PROBLEM: PLANNED RESPITE AND OTHER TEMPORARY ADMISSION TO RAC INCREASES THE NUMBER OF PERMANENT ADMISSIONS**

Respite care is provided in aged care facilities to provide a planned short-term break for a primary carer or to provide 'top up' care to a person living on their own in the community. To access planned respite, a person is required to undergo an ACAT assessment. A respite care approval entitles a person up to 63 days of respite care in a financial year. Respite does not offer the resident security of tenure.

Many YPIRAC are entering RAC for residential respite prior to being permanently admitted. AIHW data indicates that in 2017-18 there were 2,655 respite admissions of younger people, and of these, 1,577 (60%) became permanent admissions. Given that there were only 2,578 admissions to aged care last year, it also suggests that around 60% of people taking up a permanent place in aged care use respite as part of the pathway. Respite care in RAC can therefore act as a 'fast track' to permanent aged care.

"I was receiving home care 3 days a week and living with a friend who was my primary carer until she was diagnosed with cancer in 2015. She needed a 2-week break while she was receiving chemotherapy and I went into a nursing home for respite. What was expected to be a 2-week stay became 7 months after I was bullied into signing permanency forms.

"Frightened, I felt like I had no other choice. They said to me, 'You either sign these forms or you'll be out on the street'."

Brenda Evans – 52 years old

➔ SOLUTION:

To enable system reform to minimise the number of young people admitted to RAC post 2025, the NDIS should cease allocating funding in people's plan to pay for RAC. Participants should no longer be allowed to use NDIS funding to purchase an aged care bed, except in exceptional circumstances.

People who entered RAC prior to 2025, should have access to grandfathering arrangements.

There may be individual circumstances that require flexibility in how this solution is applied, for example, in remote indigenous communities, where resources must be culturally safe. In particular circumstances, an application could be made to the CEO for a special determination. The CEO should publish a report quarterly on how many exceptions to this provision are granted and why, as well as an explanation of actions undertaken to address the ongoing need for younger people to access RAC.

➔ PROBLEM: PEOPLE UNDER 65 ARE ENTERING RAC VIA THE TRANSITION CARE PROGRAM (TCP)

People exiting the hospital system may be offered the Transition Care Program (TCP) in RAC as a substitute for a slow stream rehabilitation support. Under the TCP, people can access physiotherapy, occupational therapy and social work, and either nursing support or personal care. TCP also provides medical support such as GP oversight, case management including establishing community supports and services and, where required, identification of residential care options.

Many younger people with complex needs in hospital are accessing the TCP when they are deemed medically stable, but have no discharge destination. NDIS eligible people may be awaiting a planning meeting, plan approval, funding for home modifications, or for the home modifications to be completed. Further delays can occur in the wait for a determination on their eligibility for SDA or while searching for suitable SDA. In 2017-2018, 900 people under 65 accessed the TCP nationally.

Eligibility for TCP is determined by ACAT in the hospital setting. It is usually for 84 days, but can be extended to 126 days. Once a younger person is established in RAC, it is likely that an ACAT will assess them as eligible for permanent admission to RAC.

➔ SOLUTION:

By 2025 NDIS eligible people should not be able to access the TCP. The NDIA and health will be required to monitor the market development of age-appropriate residential rehabilitation options for people with complex needs, and take a market stewardship role to stimulate market underdevelopment.

The NDIS can provide individuals with funding for short-term accommodation, which can take place in a variety of settings. As the market of short-term accommodation providers matures, people will no longer look to RAC as a provider for planned respite. This solution is likely to require the NDIS to adopt a market stewardship role to manage any 'thin market' developments.

➔ **PROBLEM: PEOPLE UNDER 65 ARE ENTERING RAC VIA THE SHORT-TERM RESTORATIVE CARE PROGRAM (STRC)**

The Short-Term Restorative Care (STRC) program provides high intensity support for up to 56 days of care. It can be accessed twice in a 12-month period, and is aimed at reversing or slowing functional decline in older people through the provision of a multidisciplinary, goal-oriented, time-limited package.

STRC services can be provided in a residential care setting, a home care setting or a combination of both. ACATs determine eligibility for the STRC program. People under 65 admitted to the STRC program in a RAC facility may find that the search for age appropriate housing and supports falls away. This is because there is a perception among aged care and disability service providers that their need for accommodation, support and access to nursing care is being met. Individuals in the STRC program may seek ACAT approval for permanent admission to RAC at the conclusion of their entitlement to support under the STRC program.

➔ **SOLUTION:**

By 2025 NDIS eligible people should not be able to access the STRC program. The NDIA will be required to take a market stewardship role to develop age appropriate residential options for people with complex needs.

KEY POINTS

- We need to disentangle the aged care system from the NDIS
- RAC doesn't offer appropriate supports for younger people and is not set up for capacity building
- There are insufficient stop gaps or diversionary measures in the Aged Care Act to stop young people entering aged care
- The Act does not prevent ACAT from making funding decisions on behalf of the NDIS. This contravenes the NDIS Act and reduces the NDIA's ability to provide funding for community-based services for NDIS participants
- RAC providers are tailoring their services as a way to market their facilities to young people, instead of investments being made into more appropriate community-based accommodation
- There is a conflict of interest where aged care providers deliver both housing and supports, inhibiting people with disability's access to their rights under the UNCRPD and safeguards under the NDIS
- Emergency and planned respite leads to permanent admission to RAC. Suitable alternatives to respite care need to be found to take younger people off the aged care pathway
- From 2025, the NDIS should stop allocating funding used to pay for RAC, except in exceptional circumstances
- Transition Care Programs and Short-Term Restorative Care are being used as a substitute for slow stream rehabilitation and community-based short-term accommodation. Alternatives to aged care should be developed by the NDIA and health systems in both these markets, with access to these aged care programs ceasing for younger people by 2025

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PATHWAYS OUT:

The need for alternative housing options

This chapter highlights the predicament of young people remaining in RAC because there is an inadequate supply of housing options that they can choose from in order to live independently in the community. The chapter covers the problems in market provision for a range of housing needs and the solutions to increase this supply.

"I was told by the Aged Care Assessment Teams that there was no smaller and age appropriate accommodation available, and then I was never contacted again once in aged care. I was almost lost to the aged care system and every now and again I would call up to find out if there was anything available for me, but because I had a bed to sleep in, I never reached the urgency level. I basically had to be homeless or a younger person with parents that were about to dump me on the steps of DHS before I would get to the urgent stage of being first in line and before the next option became available."

Anna Freeland* - 61 years old

"Dementia residents regularly get lost and come into my room in various states of undress, sometimes taking my things or peeing(!) on them."

"Nurses and managers and my GP keep telling me to find somewhere else to live but no one has found me anywhere. Current living situation is unsuitable and depressing for a young person with the physical and cognitive disabilities..."

Janice Edwards* - 35 years old, in RAC 6 years

"My NDIS plan isn't giving me what I need while living in the nursing home. I used to have up to 500 hours of therapy every year and now I only have 60 hours. I was making improvements and wanted to keep this up.

"I should be treated like a human being."

"I'm a very determined person and I want to walk. Reducing my physio means I'm not reaching my goal of walking. I don't know how to speak up for myself. It takes so much time to do everything. I don't have a support coordinator in my NDIS plan who could make sure I get what I need, including moving out. My current case manager said she doesn't know anything about housing and can't help me."

Lisa Corcoran – 43 years old, in RAC for 6 years

The range of barriers that prevent young people leaving residential aged care has been discussed in earlier chapters. These include the impact of permanent care in an unsuitable setting, such as diminishing skills, motivation and agency for major life changes, deteriorating mental and physical health. The effects of social isolation and reduction in social resources; lack of rehabilitation services and slow access to NDIS supports, particularly SDA funding, all contribute to keeping young people in RAC. This chapter focuses on the lack of appropriate accommodation alternatives and highlights how this is a significant barrier.

Lack of timely access to the housing and support that people with complex disabilities need to live in the community is one of the key reasons young people are forced to live in RAC. This is also why it is hard for them to leave. Improving the range and scale of community-based housing and support will reduce the flow of young people into RAC, and expand opportunities for them to move out and live independently in the community. It is critical that NDIS funding to increase these options is well targeted to create the diversity of housing options that young people with disability require.

LACK OF HOUSING FOR PEOPLE WITH COMPLEX NEEDS

➔ **PROBLEM: CURRENT HOUSING OPTIONS FOR PEOPLE WITH COMPLEX NEEDS ARE LIMITED**

People with disability experience multiple challenges in accessing affordable and appropriate housing - they face severe shortages of social and affordable housing, additional living costs, and the need for dwelling modifications, which may preclude private rental options.

Of the 390 properties listed on the Summer Foundation's The Housing Hub website in early 2019, only 5 were private properties for sale and 25 for private rental. The rest were social and community housing, SDA properties, Supported Residential Services, and rooming houses.

Very low incomes, low workforce participation and lack of capital exclude most people with disability from home ownership. To participate in the community, people with disability need stable housing of appropriate design, and located where they can access critical supports and services. Regulations governing residential building standards do not require housing to be built to accessible standards. Most housing is not accessible and there is little information or visibility of housing which may be accessible. These are likely to be significant barriers to independent living for people with disability.

People with disability frequently rely on social housing provided by state governments as an affordable housing option. According to the Australian Parliament house website, Australia ranked 29/29 in OECD countries for relative poverty risk of people with disability in 2011 - indicating that this cohort of Australians are likely to be highly reliant on public and social housing because their poverty factors them out of the private housing market.

While some state governments have committed to targets for building new accessible housing, audits by the Australian Network on Universal Housing Design highlight that these have largely not been met. People with disability seeking suitable housing in social housing systems around Australia can face significant waiting times.

Group homes have been the dominant housing model for people with complex support needs over the past 20 years. For example, recent analysis of demand for SDA by the Summer Foundation indicates that around 84% of current supported accommodation places in NSW are in group homes. The remaining 16% of places, in small and large institutions, are to be phased out.

In the NDIS environment, which supports individual choice and control, many people with disability will be looking for a wider range of housing options suitable for diverse living arrangements. People with disability want to decide where and with whom they live, as any person would.

This means housing options best suit people's needs where:

- Flexible supports facilitate capacity building and living meaningful and satisfying lives
- Opportunities to build and maintain relationships with family, friends and acquaintances are maximised and new connections and relationships can develop
- There is a choice in who you live with, whether you live on your own or with family or friends

These opportunities and choices have not been present in disability housing models that currently dominate the market.

State jurisdictions have reduced the mainstream housing supports they have funded and provided, such as tenancy advice and private rental market assistance to NDIS participants, which is an additional roadblock to accessing housing options.

SOLUTIONS:

The Accessible Housing project of the Australian Building Codes Board (ABCB) now underway is examining if the National Construction Code (NCC) should be changed. The ABCB is considering making it a requirement that all new housing is to be built to accessible housing standards that comply with Livable Housing Guidelines. Should this project result in changes to the NCC, the flow-on effect would be an increased stock of accessible housing across the housing market.

The role of state and territory governments in providing accessible housing in social housing systems remains a crucial response to the housing needs of people at risk of living in aged care. They need clear strategies to improve access to appropriate and secure housing. Jurisdictions must increase supply of accessible social housing, and ensure that people with disability and complex needs have timely access to social housing.

➔ **PROBLEM: MARKET FAILURE IN PROVISION OF TRANSITION AND CRISIS HOUSING**

Young people with complex disability needs are frequently reliant on short-term and long-term housing options to avoid admission to RAC. Currently market supply does not meet demand. Innovative models are being developed, but progress is slow.

Temporary or short-term housing is needed for a range of interim and/or urgent situations and complex needs. Interim housing options are needed where a person has approved NDIS funding support to move to more appropriate housing, but this housing is not yet available (e.g. not built yet).

Urgent housing options are needed where existing housing arrangements are no longer available or break down (perhaps where increased supports are needed).

The Office of the Public Advocate released a report in 2018 on the difficulties faced by people with complex and challenging support needs, in accessing adequate NDIS supports, including housing³². The report identified a cohort of people with disability who were unable to live sustainably with others because of their complex behaviour and low thresholds for frustration and distress.

Housing options for many of this group were reduced to public or social housing - much of which was available only after long wait times. Other factors reduced the suitability of this housing, including the difficulties caused by inadequate space for safe staff support activities and refusal by the NDIA to fund modifications.

People with complex disability support needs and complex behavioural needs can be at risk of homelessness and poor health. Lack of adequate supports, including specialised housing, can create a pathway to RAC through hospital or emergency department admission.

➔ **SOLUTIONS:**

Supply of transition and crisis housing can be stimulated by NDIA market stewardship initiatives such as incentive funding for innovative temporary/transition housing prototypes. Direct funding of selected housing providers by the NDIA under market stewardship can be targeted to 'last resort' accommodation for people with complex needs who are at risk of admission to RAC because of imminent homelessness.

In order to release SDA funding for urgent temporary housing options such as crisis housing, the SDA Rules must be amended to enable funding of 'alternative interim options'.

The Summer Foundation has developed a prototype of an interim housing unit that can be rapidly located to provide housing for someone who is waiting for accessible housing to become available or for home modifications to be completed.

The prototype looks just like any other small house – it has a living area, bedroom and ensuite, kitchenette and laundry. Assistive technology increases the occupant's independence, safety and security. The prototype unit aims to have a long-lasting impact on the way people with disability are discharged from hospital and into the community.

³² Office of the Public Advocate (2018) The Illusion of 'Choice and Control' Office of the Public Advocate, Victoria.

➔ **PROBLEM: SDA PAYMENTS WERE SLOW TO START FLOWING**

The SDA framework under the NDIS has brought the potential for significant investment in a variety of quality housing types for people with complex disabilities. The Summer Foundation has done extensive work since the introduction of the SDA framework to promote the potential to invest in new accessible housing, and has developed resources and tools to help NDIS participants to understand the path to new housing options, with the support of their NDIS funding.

In its first 2 years of operation, the SDA framework has mainly facilitated payments to NDIS participants living in existing supported accommodation (under old models) transitioning to the NDIS. As of June 30 2018, only 22 NDIS participants living in RAC had left with SDA funding in their NDIS plan.

A 2019 AHURI report established that the SDA industry is able to provide an affordable housing market that is driven by client choice, and does not need a safety net for investors.³³ Beer et al found that among the many impediments to SDA success and efficiency which are within government control, is the need to provide better data, in an open and transparent way, to providers in the diverse SDA 'sector'.

Recent changes to the SDA framework are likely to lead to better outcomes in the future. These changes include fast tracking SDA approvals for those with the most urgent needs (aged care and hospital), setting up a national panel for SDA approvals and removing previous roadblocks by not requiring all other options to be exhausted before applying for SDA.

There is growing interest among a range of commercial and not-for-profit organisations in using the SDA framework to develop quality new housing options.

➔ **SOLUTIONS:**

More detailed information is critical for market development of SDA housing. Housing developers are dependent on the NDIA to make information about the SDA decision process available. This is essential to their planning and decision-making. An increase in specialist housing development will also be assisted by practice guidance tools containing checklists and examples.

The SDA framework must be updated to ensure that it achieves choice and control for participants, particularly in regard to choice of building type and location, and choice of whether to share housing or not.

33 Beer, A., Flanagan, K., Verdouw, J., Lowies, B., and Zappia, G. (2019) Understanding Specialist Disability Accommodation funding, AHURI Final Report 310, Australian Housing and Urban Research Institute Limited, Melbourne, <http://www.ahuri.edu.au/research/final-reports/301>, doi: 10.18408/ahuri-3219701.

➔ **PROBLEM: NDIA PLANNING APPROVALS CAUSE HOUSING DELAYS**

In addition to the delays in entering the NDIS, YPIRAC can also experience a delay in gaining NDIA approval for meeting SDA eligibility requirements. Young people are only admitted to RAC following an assessment by an ACAT. This assessment determines their eligibility for permanent aged care admission, a process that includes an exploration and rejection of all alternative housing options. However, to gain approval for SDA funding, they are then required to undergo another NDIA assessment. This is to determine if their level of functional impairment satisfies SDA Rule requirements for 'Extreme Functional Impairment', and, prior to the recent changes, that all other housing options have been considered. This double process causes delays, and roadblocks for YPIRAC who wish to leave RAC.

Most YPIRAC require SDA funding to leave RAC. They experience considerable uncertainty as currently the NDIA has not set timeframes for completion of their decisions on SDA.

Roadblocks can also occur where long-term accommodation is not available, and 'interim' or 'step-down' housing options are needed as a stepping-stone to more appropriate options.

➔ **SOLUTIONS:**

The SDA decision-making process for YPIRAC can be simplified through an NDIA policy direction that these participants, who have already been assessed as eligible for permanent aged care, are also deemed as satisfying SDA Rules requirements for an 'Extreme Functional Impairment'.

The process can be further streamlined through the publication of NDIA completion target periods for SDA approvals.

NDIA funding for 'interim' or 'step-down' accommodation options would create greater flexibility and reduce delays in YPIRAC moving out of aged care.

KEY POINTS:

- There are severe shortages of accessible social and affordable housing
- Current housing market supply does not meet the needs of people with complex disability needs
- Delays in SDA payments have been problematic for SDA market growth, although are now being addressed
- NDIA planning approvals cause delays and roadblocks for young people trying to leave RAC

9

PATHWAYS OUT:

How can we get young people out of RAC and support them while waiting to exit?

"I was able to move out of the nursing home by pure luck. In 2008, *Today Tonight* did a story on alcohol fuelled violence and I was on there to tell my story. A coordinator of a supported independent living residence saw the show and came and saw me the next week. They were building a place for young people...It was four years before the house was completed and I was able to move. As soon as the front tyres of the bus hit the road out of the nursing home, I said "GIDDYUP!!!"

"I felt like I was floating. I had been very melancholy, but at that moment in time that all disappeared. I thought to myself, 'Anything is possible now'. I wasn't being forced to live in these gated premises."

James Nutt – 35 years old

Renewed hope of positive changes to stop young people being forced into RAC now exists with the release of the Younger People in Residential Aged Care - Action Plan in March 2019. The plan, which does not yet include a detailed implementation plan, spells out in broad terms how all young people will benefit from improved hospital discharge, faster NDIS planning and approvals, and more highly skilled planners. (Many of these issues have already been highlighted in earlier chapters.) The targeted resources will complement the enhanced SDA Rules and the complex pathways strategies.

In this chapter we identify exciting solutions contained in new prototypes of temporary housing, and in models to improve collaboration in system interfaces. Taking into account that the implementation of the Action Plan will take at least 6 years to substantially reduce the numbers of YPIRAC, we provide solutions for improving life for young people currently 'stuck' in permanent care.

IMPROVEMENTS FOR YOUNG PEOPLE WHILE IN RAC

As earlier chapters have discussed, living in RAC is damaging to the health and wellbeing of young people. YPIRAC are likely to have poor outcomes, and these are compounded over time - the longer they live in RAC the worse their outcomes are.

Permanent admission status and living in an environment geared to the needs of frail older people leaves them with feelings of hopelessness and helplessness. Where there is hope that they may leave RAC, and plans are in place for alternative, suitable accommodation of choice, their health and wellbeing improves.

As the Younger People in Aged Care- Action Plan defines 6-year goals for those already in aged care, to be able to find alternative housing and supports (if they chose to do so), it is likely that there will still be people aged under 65 in RAC post 2025. Until RAC is no longer needed as an option for young people, it is better to define this at the outset as a transitional option, rather than a permanent one. This will give tangible hope that finding accommodation of their choice is a mandated goal.

➔ **PROBLEM: RAC STAFF ARE NOT TRAINED TO SUPPORT INDEPENDENCE**

As YPIRAC lose skills over time while in aged care, the capacity building required to transition to more suitable housing is a major issue. There is little opportunity provided in RAC for capacity building activities. There are no structures or systems for learning or re-learning skills in cooking, preparing meals, shopping, managing continence etc, unless there are NDIS plans in place that will fund them. There is little evidence from existing plans of funding allocations for re-learning essential skills. The overall average plan amounts for YPIRAC from Senate Estimates does not indicate that this has been achieved yet.

Aged care staff have minimal knowledge of complex disabilities and the NDIS and this is leading to poor outcomes for people under 65, particularly the loss of skills that would otherwise enable a person to transition into the community.

The impact of minimal knowledge regarding complex disabilities was observed by the Summer Foundation during training delivered to RAC staff in 2018. During the training RAC staff were given information about the NDIS, its value to YPIRAC, and examples of young people with very complex needs who had moved out of RAC. Following this, none of the RAC staff reported that they had any young residents with the capacity or potential to move out.

"When I was in rehab it was about becoming independent. In aged care they want to do everything for you – they think they're doing you a favour, but it's not supporting your independence or building your capacity."

Deborah Huismann – in her mid 50s

➔ **SOLUTION: RAC AS A TRANSITIONAL OPTION**

Until RAC no longer offers accommodation for young people, aged care admissions must be regarded as transitional rather than permanent. It can then be seen as an interim option only, while alternative services, supports and accommodation options are established. A change in status can be operationalised by policy and procedural measures such as:

- Mandatory linking of young people into the NDIS prior to entry into RAC
- Proactively investigating housing options with NDIS supports during ACAT assessments, so that alternative and preferred long-term housing options can be identified early

➔ SOLUTION: REDUCE DETERIORATION IN HEALTH AND WELLBEING OF YPIRAC WAITING TO TRANSITION OUT

In addition to the commitments in the Action Plan for YPIRAC for faster access, better planning and integrated supports (which includes commitments contained in the Complex Support Needs Pathway for all NDIS participants in aged care), the following solutions are also critical to ensuring that YPIRAC are supported in aged care facilities, over and above NDIS supports.

- Funding for investment into maintenance of function and wellbeing after entry
- YPIRAC linked with health services for active rehabilitation support (complementary to extra social leave availability)
- Active support for maintenance of social and community networks
- Access to appropriately skilled staff to deliver care in RAC
- For YPIRAC who are not eligible for the NDIS referral to relevant disability organisations such as advocacy services must be made available. YPIRAC in this category should have access to supports to consider options to choose alternative accommodation and must be able to receive disability supports and have a better quality of life.

➔ SOLUTION: FACILITATE THE BEST OPPORTUNITY TO MOVE OUT

While there are still young people in aged care, they may rely on aged care workers to assist them to access the NDIS. For this reason, as an interim measure, it would be beneficial to require training for aged care providers on NDIS eligibility/access requirements, and key NDIS supports that are essential to opportunities for people under 65 with complex disability support needs to move out.

CAPACITY BUILDING AND SUPPORT COORDINATION

Support coordination is a critical NDIS support for young people living in RAC to build their capacity to exit and return to life in the community. A key part of this is to support them to find the appropriate support services and housing options.

"It would be helpful to go through a discharge planning process when you leave the nursing home.

"You need to have someone to support you so that you're not letting the same environment prevail once you leave. It isn't just about exiting the nursing home, it's about being able to live in the community."

"There needs to be a pathway once you leave, perhaps tied to the NDIS.

"You need to have someone who looks at supports, therapies, housing, technology and work. They help you learn new skills and to manage your own plan. You need to integrate into the community you are part of, which is what I'm sadly still lacking."

Vicki Wilkinson, in her late 40s

Support coordination is a new role in a new system and there are significant challenges for the development of this market. New roles mean new knowledge and skills are required by those delivering these services. Many service providers don't understand how to perform this role for people with complex housing and support needs.

This is particularly so for groups in the community such as indigenous people with disability. There is an acute shortage of Aboriginal support coordinators.

People with complex needs, including those with issues around communication, cognition, memory, information processing etc, require tailored individual responses from highly skilled teams to achieve community living outcomes.

The current challenges in the support coordination market include:

Workforce growth without sufficient investment in skills and knowledge.

The growth in the support coordination workforce has seen many disability support workers transition into a support coordination role without the necessary skills and knowledge to work within the complexity of the role. Often the culture and skills mix of these practitioners are different from what is required to deliver support coordination. There is much anecdotal information about poor quality support coordination services and funds wasted on these services. The required skills and competencies for support coordinators is unclear, and there is a lack of professional development opportunities that would align services with the needs of participants and improve service quality.

Over-reliance on generalist support coordinators.

The Summer Foundation is also learning of significant uncertainty in the support coordination market, particularly for specialist support coordination. We know that very few people are funded for specialist support coordination, or have limited periods of funding. Insufficient support coordination funding in plans and/or removal from plans prematurely when the participant still needs this type of support, can lead to increased demand in the future.

Insufficient support coordination to navigate thin markets.

Support coordinators are a key tool for the NDIS in assisting participants with complex needs, to find the services they need, including in thin markets. Funding decisions in NDIS plans which result in inadequate support coordination hours and duration for participants will undermine participant outcomes, as well as business viability for support coordination providers. Individual plans should have sufficient hours funded to pay a range of professionals to coordinate their work to support individuals to reach their goals.

A poorly functioning support coordination market ultimately holds back the ability of participants to utilise their NDIS funding to achieve goals, such as finding a new home and achieving more independence.

SOLUTION:

Capacity to engage in goal setting and planning is often hampered by limited knowledge of the possibilities for life beyond RAC. If young people in nursing homes are to benefit from the opportunities available through the NDIS they require highly skilled, specialist support to increase their capacity to be actively involved in planning their future, setting goals, planning and choosing appropriate services and supports.

CASE STUDY: UPSKILL

The Summer Foundation has developed the “UpSkill” initiative to support capacity building for professionals providing specialist support coordination, in order to improve services to participants with complex support and housing needs. (www.summerfoundation.org.au/project/upskill/)

This project seeks to increase capacity of the support coordination workforce by:

- Building a rigorous evidence base on quality practice from the existing literature. The evidence base will be continuously expanded during the project through an evaluation partnership with La Trobe University
- Developing and disseminating knowledge and tools, including case studies of successful aged care avoidance and exits from aged care, and a toolkit for support coordinators working with young people in aged care
- Curating an online Community of Practice (CoP) of expert support coordinators who specialise in supporting young people to avoid or exit aged care
- Empowering participants with complex needs to shape the market through journey mapping, and implementing a connection service to access a suitably qualified network of support coordinators regardless of where they live

Together, these activities help to address thin markets by simultaneously building the capacity of the workforce and also connecting the supply of skilled support coordinators with NDIS participants who are seeking support coordinators that have specialised knowledge and skills.

SECURING PRIMARY AND COMMUNITY HEALTH AFTER EXIT

➔ PROBLEM:

Currently primary and community health services do not meet the needs of people with high and complex disabilities, forcing many to stay in hospital longer than is necessary, or return frequently to hospital increasing their likelihood of being forced into RAC.

➔ SOLUTIONS:

To fix this problem we need:

- Primary health services to have increased knowledge and capacity to meet complex health care needs in the community
- Slow stream rehabilitation services to be available in the community
- Preventative health care to be available in the community and responsive to people with disabilities with high and complex needs

ACHIEVING IMPROVED HOSPITAL DISCHARGE

Health and NDIS interface issues discussed in Chapter 6 show where the systems fail to dovetail in an effective way. There are many challenges in fixing system mismatches as these can differ significantly in each jurisdiction and region.

CASE STUDY: COLLABORATIVE DISCHARGE APPROACH

The Summer Foundation has developed the Collaborative Discharge Approach (CDA) – a model that outlines a staged process of interaction between the health system and the NDIS. It aims to create a seamless pathway for younger people with complex needs to access health, NDIS and housing supports. Implementing this approach can result in reducing the duration of unnecessary stays in hospital, fewer young people entering RAC, and timely exit from hospital with high quality housing and supports.

The CDA sets out activities that secure:

- A consistent support for the person with disability
- Early engagement with the NDIA access team and senior planner
- Functional language for documenting needs
- An early, flexible plan – key for support coordination
- Early exploration of housing
- Collaboration between health and private providers
- Timely sourcing of NDIS providers
- Real world trials of equipment and home environments
- Post discharge, support coordination monitoring of people's needs to avoid readmission



As a blueprint for how health and support coordination can work effectively together, the approach is backed by a number of Summer Foundation teams. They are currently overseeing and supporting implementation in pilot sites in Victoria (Ballarat, Barwon, Austin and Alfred Health Networks), Sydney (South West LHD), and in Brisbane. The Summer Foundation is already aware that in pilot sites the CDA is having significant outcomes for people with complex disability needs.

KEY POINTS:

- RAC needs to be reframed as transitional housing when using it as a housing option for young people with disability. If aged care is presented as a transitional option while appropriate accessible housing is found it means that a young person and their supporters are less likely to accept it as a permanent arrangement
- There is little opportunity in RAC for capacity building and aged care staff do not have the required knowledge to build capacity and support independence
- Support coordination is a critical NDIS support for young people in RAC. There are many challenges around the new support coordinator workforce. YPIRAC need highly skilled and specialist support to implement their plans
- The Summer Foundation's UpSkill initiative seeks to address the professional challenges that support coordinators are facing
- Hospital discharge processes are a significant issue. The Collaborative Discharge Approach provides a blueprint for how systems and services can work together effectively to reduce the length of time in hospital and reduce the number of young people entering RAC

10

RECOMMENDATIONS

Aged care is a highly unsuitable housing and support option for young people. Continuing to force young people into aged care is a breach of our human rights obligations and should no longer be necessary with the introduction of the NDIS.

This submission has demonstrated how damaging this is for people aged under 65. Major system reform is overdue to stop young people entering RAC, and to enable young people who are living there now to have viable options to leave if they choose to.

The NDIS has the potential to achieve this goal. However, while it remains in its formative stages and the market of disability supports providers is immature, RAC will continue to be a 'provider of last resort' for people with complex disability support needs.

With the publication of the Younger People in Residential Aged Care – Action Plan, system reform is underway with renewed national commitment. Our recommendations are geared to the short-term and longer-term changes as framed in the timelines of the Action Plan. They are focused on making sure that people with disabilities who are under 65 are not forced into and stuck in aged care as a result of the systemic failures we have described.

The recommendations below are designed to address these systemic failures and create a future where young people with disabilities can live in the community with suitable and high quality housing and support.

1. REINFORCE ACTION PLAN TARGETS IN THE NATIONAL DISABILITY AGREEMENT

- 1.1 Recommendation:** Government to reinforce targets in the National Disability Agreement to reduce the number of YPIRAC, and monitor progress through:
- Its current performance indicator: "Percentage of younger people entering, living in, and exiting permanent residential aged care"
 - The adoption of additional indicators covering mainstream health and housing measures, as well as specialist disability services
 - The introduction of benchmarks, targets and measures into its performance framework that address progress in preventing young people being forced into aged care
 - Improving its reporting through the Report on Government Services (ROGS) to improve the timeliness of the data by releasing it within 6 months of the end of the financial year it reports against, and increase its coverage of new benchmark indicators

2. ASSIST YOUNG PEOPLE TO EXIT AGED CARE

- 2.1 Recommendation:** All existing young people in aged care should have access to specialist NDIS planners who are trained and focused on their needs.
- 2.2 Recommendation:** NDIA to provide all YPIRAC with support coordination to assist them with their Access Request and preplanning. The same support coordinator should be available to support them at their planning meeting, to work with them on plan activation, and to identify appropriate alternative housing solutions.
- 2.3 Recommendation:** NDIA to provide YPIRAC who have a goal of leaving RAC funding for Allied Health Assessment for Exploring Housing Options, and build in a plan review after 3 months to transition towards their preferred alternative to RAC.
- 2.4 Recommendation:** Government to prioritise an investment in workforce development of support coordinators, including training in working with people who have complex disability and health needs, and development of expertise in exploring accessible housing options for this cohort.
- 2.5 Recommendation:** All jurisdictions to fund dedicated independent advocacy services sufficient to assist YPIRAC with Access Requests, preplanning support and advocacy through the access and planning process. We estimate that this equates to 20 FTE advocacy roles nationwide.
- 2.6 Recommendation:** All jurisdictions to commit to policies that:
 - a. Increase knowledge and capacity of primary health services to meet complex health care needs in the community
 - b. Make slow stream rehabilitation services available in the community
 - c. Make preventative health care available in the community and responsive to people with disabilities with high and complex needs
- 2.7 Recommendation:** Improve YPIRAC's access to the NDIS, including access to assistive technology, home modifications and SDA funding.

3. RESOLVE GAPS IN THE INTERFACE BETWEEN THE NDIS AND THE HEALTH SYSTEM THAT LEAD TO YOUNG PEOPLE BEING ADMITTED TO AGED CARE

- 3.1 Recommendation:** National action by health services and the NDIA to identify and address interface problems by:
 - a. Investigating and tracking service gaps such as agreement on responsibilities for funding community nursing for people with complex needs
 - b. Committing funding to resolve the identified gaps in services
 - c. Establishing joint escalation procedures and processes for people with complex support needs
 - d. Establishing an NDIS-health interface advisory group of community stakeholders

4. MONITOR OUTCOMES FOR PEOPLE WITH COMPLEX NEEDS IN THE HEALTH SYSTEM, IDENTIFYING THOSE ENTERING AGED CARE

- 4.1 Recommendation:** Government to create a national data collection and reporting framework to monitor outcomes for people with disability and complex needs in the health system that would:
- a. Provide post-discharge follow-up to measure outcomes and improve processes
 - b. Incorporate a feedback loop to identify deterioration in health and wellbeing and trigger remedial actions
 - c. Report publicly on the reasons and length of time NDIS participants stay in hospital beyond their discharge date
 - d. Identify the number of hospital patients being discharged into aged care, and the drivers for each young person's admission

5. BUILD THE CAPACITY OF HEALTH SERVICES TO SUPPORT PEOPLE WITH DISABILITY TO LEAVE HOSPITAL WELL AND AVOID AGED CARE

- 5.1 Recommendation:** Commonwealth and state government health departments to collaborate on capacity-building measures that include:
- a. Mandatory training for hospital staff involved in discharging NDIS participants to ensure competence in NDIS (principles, processes and terminology), general disability awareness and supports for people with complex support needs, and the use of rapid response tools designed for practitioners
 - b. Funding for discharge planning communities of practice across the country to share expertise and resources, and support local health champions who are NDIS experts and can support complex discharge processes
 - c. Assessment protocols for early identification of people with complex disability support needs, and develop processes to escalate supports early
 - d. Supports for people with disability to undertake 'pre-planning' while in hospitals, including education and information materials about the NDIS
 - e. Relationship-building with primary care, housing, support coordination and disability support providers to assist people with disability to seamlessly transition from hospital back to the community
- 5.2 Recommendation:** Fix the hospital discharge pathway so that young people are not discharged into RAC by making hospital discharge a COAG strategic priority; use funding such as NDIS ILC funding for hospital capacity building; and expand the Collaborative Hospital Discharge pathway pilot.

6. BUILD NDIA CAPACITY TO SUPPORT PEOPLE WITH COMPLEX NEEDS IN HEALTH SETTINGS

- 6.1 Recommendation:** NDIA to build its capacity to support people with disability in hospital by:
- a. Creating a fast track system for people with disability residing in hospitals to have their access request processed urgently and planning to commence within 2 weeks of access request lodgement
 - b. Partnering with hospitals to develop NDIS plans for participants based on a draft NDIS plan developed by hospitals and reviewed by NDIA specialist planners
 - c. Identifying NDIA specialist planners who have undertaken training on clinical support requirements of people with complex disability and health needs to work in acute and subacute settings; and who are directly contactable by health services
 - d. Funding support coordination and specialist support coordination while participants are in hospital, including through short-term plans
 - e. Fast-tracking SDA decision-making for people with complex support needs exiting the acute and sub-acute health sector to address the absence of suitable housing

7. STIMULATE ACCESSIBLE HOUSING SUPPLY

- 7.1 Recommendation:** The NDIA to publish more detailed information for NDIS participants about the SDA decision process and the information and evidence taken into account in making decisions. This should include practice guidance tools including checklists and examples.
- 7.2 Recommendation:** COAG to amend the National Construction Code so all new homes are required to be built to minimum Livable Housing Australia Guidelines.
- 7.3 Recommendation:** All levels of government to work together to improve access to accessible and affordable housing for NDIS participants including those in RAC, through the use of SDA and through social and affordable housing systems.
- 7.4 Recommendation:** Expand online housing directories that enable people with disability at risk of aged care to see accessible housing vacancies for people with disability, such as the Summer Foundation's The Housing Hub website.
- 7.5 Recommendation:** Government to fund research to monitor outcomes of the NDIS' SDA initiative, including the outcomes that young people in aged care achieve by moving out into community based, contemporary housing.

8. IMPROVE NDIS PLANNING AND APPROVALS TO SPEED UP HOUSING ROADBLOCKS FOR YPIRAC

- 8.1 Recommendation:** The NDIA to set performance timeframes for SDA funding determinations to provide greater certainty for YPIRAC. For participants who have identified an immediate SDA option, and have requested SDA funding in their plan, there should be a 28-day turnaround for decisions on SDA.
- 8.2 Recommendation:** The NDIA to fund 'interim' or 'step-down' housing options when long-term housing options are not available, or when a step-down option is needed to assist the person to transition out of RAC, or to avoid admission to RAC when they are transitioning out of health care.

9. INCREASE TRANSITION HOUSING OPTIONS TO PREVENT ADMISSION TO RAC

- 9.1 Recommendation:** The NDIA to stimulate growth of temporary/transition/crisis short-term accommodation by utilising market stewardship to directly fund 'last resort' accommodation, including rapid response options for participants with complex needs who are at risk of admission to aged care because they have additional needs such as homelessness, mental health issues, dual/multiple diagnoses, behavioural issues and/or chronic social disadvantage.
- 9.2 Recommendation:** Flexible funding packages should be established to provide an interim housing solution for young people in and at risk of entering RAC. Housing alternatives include dedicated transitional living centres, accessible mainstream rental housing stock and re-purposed SDA transitional housing. Flexible packages must include funds for contingencies to allow for rapid changes in health circumstances and the ability to provide a rapid response to changing needs. This funding should be managed by the NDIA.

10. IMPROVE SUPPORT FOR YOUNGER PEOPLE WHILE IN RAC

- 10.1 Recommendation:** The Royal Commission to examine the reasons why any younger people living in RAC have not been accepted into the NDIS, and how the aged care system can respond to people with disability who are not NDIS participants.
- 10.2 Recommendation:** The NDIA and aged care to collaborate on policy and procedures to redefine admission to RAC for younger people as a 'transition' status rather than a permanent status. These should include:
- a. NDIS funding for investment into maintenance of function and wellbeing after entry
 - b. YPIRAC linked with health services for active rehabilitation support
 - c. NDIS funding support for maintenance of social and community networks
 - d. Access to appropriately skilled staff to deliver care in nursing homes
 - e. Instigate waivers so young people are not obliged to sell their homes to pay for a bond and are not required to pay large daily fees
 - f. NDIS funding for support coordination and the engagement of intermediary organisations to support YPIRAC to continue to explore alternatives while living in RAC
 - g. ACAT staff to refer YPIRAC who have been assessed as 'not eligible' for the NDIS to relevant disability organisations, such as advocacy agencies, in order to ensure that they have access to supports to consider alternative accommodation options if they choose to do so
 - h. Department of Health to carry out an annual audit of YPIRAC in conjunction with Aged Care providers
- 10.3 Recommendation:** Competency and skill in the aged care workforce to be up-graded by requiring a working knowledge of NDIS eligibility/access and key NDIS supports essential to opportunities for people under 65 to move out.

11. SEPARATE AGED CARE FROM THE NDIS

These final recommendations are geared to address the short-term and longer-term goals of the national action plan for younger people in residential aged care and require reforms to the Aged Care Act. They reinforce the goal to disentangle the aged care and disability systems in the short term, and in the longer term remove aged care as an option for young people as other, contemporary options become available in the market. In some thin markets and other exceptional cases, aged care should continue to be an option to avoid people being displaced from communities or stuck in hospital.

Immediate changes

- 11.1. Recommendation:** To formalise the principles related to younger people in aged care, the following matters relating to the assessment of people under 65 years for a Commonwealth funded aged care place should be set out in the Approval of Care Recipients Principles 2014.
- a. Australian residents under 65 years of age with a permanent and significant functional impairment requiring housing and support are the responsibility of the NDIS. ACATs should direct these people to the NDIS in the first instance
 - b. For people under 65 who are at risk of RAC and do not meet NDIS residency requirements, ACATs cannot undertake an assessment without endorsement by the NDIA
 - c. ACATs should assist people under 65 requiring palliative care to access the palliative care system
- 11.2 Recommendation:** The NDIS should be responsible for making a decision about whether an NDIS participant enters aged care by following these steps:
- a. The NDIA should only agree to fund the aged care place, and relevant means-tested fees, if it is satisfied that the person could not be supported to live in the community with NDIS funded housing and supports
 - b. Where the NDIA has not yet made this decision and a younger person is seeking an ACAT for an assessment, the ACAT should refer the request back to the NDIA to determine whether aged care is a reasonable and necessary support for them
- 11.3 Recommendation:** Where the NDIA has determined that aged care is a reasonable and necessary support for the participant, and endorses an individual for an ACAT assessment, the NDIA must provide the person, and/or their nominee, with clear information outlining:
- a. How the individual RAC facility meets section 34 of the NDIS Act 2013, *reasonable and necessary*
 - b. The aged care fees payable, and an explanation that the NDIA will reimburse the participant for all applicable means-tested care fees and accommodation contributions paid as a daily payment up to certain caps. This will ensure that people can negotiate an aged care place with a provider and not face a 'gap' payment
- 11.4 Recommendation:** The NDIA should be required to publish a twice yearly report with detailed information about all NDIS participants where the NDIA has made a decision that aged care is a reasonable and necessary support with the purpose of informing the NDIS market of what services are not provided, including the locations (SA3 level), ages, disability support needs and reason for entering aged care
- 11.5 Recommendation:** People under 65 residing in RAC who have been declined entry to the NDIS on the grounds that their impairment is health-related not disability-related should be able to request an immediate review of the NDIS disability decision by the CEO of the NDIA. The CEO should be required to review the decision within 14 days. If the CEO upholds the original decision the person should be directed to a disability advocacy service with relevant expertise for assistance to assist the person consider their options.

- 11.6 Recommendation:** People under 65 who are in hospital and at risk of admission to RAC and who have been declined entry to the NDIS on the grounds that their impairment is health-related not disability-related should be able to request an immediate review of the NDIS disability decision by the CEO of the NDIA. The review can be triggered by any source (young person and/or their carer, advocate, hospital social worker and/or discharge planner). The CEO of the NDIA should be required to review the decision within 14 days. If the CEO upholds the original decision the person should be directed to a disability advocacy service with relevant expertise for assistance to review, rewrite and resubmit their access request form.
- 11.7 Recommendation:** The NDIS Quality and Safeguards Commission should develop specialist knowledge on the interface between the NDIS and the aged care sector. This must include education and training for ACATs and aged care providers, backed by a telephone advice line, and the publication of fact sheets for RAC providers. It is essential that the fact sheets indicate that they are required to comply with the NDIS Code of Conduct. Facts sheets should include advice by the Commission (in respect to the SDA framework) to RAC providers, that establishing congregate living arrangements for NDIS participants is not consistent with the intention of the *NDIS Act 2013*.
- 11.8 Recommendation:** The NDIS Quality and Safeguards Commission should develop information resources in accessible formats to educate individual participants in RAC, and their informal and formal networks, about the protections afforded to them under the NDIS Act 2013 and related legislative instruments, and how to seek redress in the event of a breach.
- 11.9 Recommendation:** The NDIA should provide younger people in RAC, or at risk of admission, with funding for support coordination and plan management to ensure that they have the means to purchase supports from a range of providers.
- 11.10 Recommendation:** The NDIS should work with expert organisations to build the capacity of support coordinators with information about the interface between the NDIS and the aged care sector, and links to training on how to work with people in aged care to build their capacity, exercise choice and control and maximise their independence.
- 11.11 Recommendation:** Support the Tune Review Recommendation that aged care providers publish staff ratios by calling for the Parliament to pass the Aged Care Amendment (Staffing Ratio Disclosure) Bill 2018 without further delay.
- 11.12 Recommendation:** YPIRAC should be eligible for 104 days of social leave per year to assist them to build confidence, social connections and a support team, as a precursor to exiting RAC.
- 11.13 Recommendation:** The provisions around the protection of the RAC resident's personal information should be reviewed to allow for better data collection and monitoring of de-identified individual and cohort outcomes.
- 11.14 Recommendation:** The Report on the Operation of the Aged Care Sector and The Report on the Funding and Financing of Age Care must each include a chapter on younger people in aged care and assess the provision of care against the revised COAG Principles, reflected in the *Approval of Care Recipients Principles 2014*.
- 11.15 Recommendation:** People with disabilities should have access to age-appropriate community based palliative care services that can meet their complex support needs.
- 11.16 Recommendation:** When a younger person enters RAC for emergency respite ACAT approval (determined either prior to entry or after) should be made for no longer than 63 days. If they are not already NDIS participants, the ACAT assessor should be required to facilitate an urgent NDIS access request on their behalf (with their consent). If the person is already an NDIS participant, the assessor must facilitate (with their consent) an immediate review of their NDIS plan on the basis of a Change of Circumstances.

Changes to the Aged Care Act to be implemented by 2025

- 11.17 Recommendation:** Post 2025, the NDIS should cease making decisions that aged care is a reasonable and necessary support for NDIS participants, except in exceptional circumstances.
- a. People who entered RAC prior to 2025 should have access to grandfathering arrangements
 - b. The exceptional circumstances provisions allow the NDIS to accommodate for individual circumstances that require flexibility, for example in very remote locations where there is no viable disability service
 - c. The CEO of the NDIA should table a report to parliament on how many exceptions to this provision are granted and why
- 11.18 Recommendation:** By 2025, end access for NDIS eligible young people to planned respite in RAC. The NDIA and Department of Social Services must take a market stewardship role to develop age appropriate short-term accommodation/respite for people with complex needs.
- 11.19 Recommendation:** By 2025, end access for NDIS eligible people to the Transition Care Program (TCP). The NDIA and state health departments should monitor market development of age-appropriate residential rehabilitation options for people with complex needs, and take a market stewardship role if necessary to stimulate market development.
- 11.20 Recommendation:** By 2025, end access for NDIS eligible people to the Short-Term Restorative Care (STRC) program.

We will end our submission with the words of Vicki Wilkinson:

"My message to you is to start liberating those who've been in aged care.

"Don't write us off. We're very much here and with it. We want to be a part of our community. It's about inclusion, not exclusion. I have a voice. I want to recover from this and flourish. Help me do this."

ATTACHMENT I

"Part 8 – Module 5: Specialist Disability Accommodation of the National Disability Insurance Scheme (Quality Indicators) Guidelines 2018[4]"

67 Applicable Practice Standards

Schedule 7 to the National Disability Insurance Scheme (Provider Registration and Practice Standards) Rules 2018 sets out the relevant NDIS Practice Standards that apply to this Part.

68 Rights and Responsibilities

Outcome: Each participant's access to specialist disability accommodation dwellings is consistent with their legal and human rights and they are supported to exercise informed choice and control.

To achieve this outcome, the following indicators should be demonstrated:

- (1) Knowledge and understanding of each participant's legal and human rights, and incorporation of these rights into everyday practice, including through reasonable adjustments or modifications to the dwelling to meet each participant's needs.
- (2) Any agreement or contract entered into with each participant, and any communication with the participant about the provision of specialist disability accommodation, including about rights and responsibilities in relation to the dwelling, is responsive to their needs and provided in the language, mode of communication and terms which that participant is most likely to understand.
- (3) Each participant's autonomy, including their right to privacy, intimacy and sexual expression is respected.

69 Conflict of Interest

Outcome: Each participant's right to exercise choice and control over other NDIS support provision is not limited by their choice of specialist disability accommodation dwelling.

To achieve this outcome, the following indicators should be demonstrated:

- (1) Organisational policies are in place that detail how perceived or actual conflicts of interests are managed. The conflict of interest policies are made available to participants in the language, mode of communication and terms which each participant is most likely to understand.
- (2) Conflicts of interest, perceived or actual, are proactively managed and documented.
- (3) The participant is supported to understand the distinction between the provision of specialist disability accommodation and other NDIS supports delivered in the dwelling. Where a specialist disability accommodation provider is delivering both specialist disability accommodation and other NDIS supports to the same participant, there are separate service agreements.
- (4) The participant's housing rights, including security of tenure, are upheld, irrespective of any decision/s the participant makes about the provision of other NDIS supports within the specialist disability accommodation dwelling (notwithstanding any matters covered by the specialist disability accommodation service agreement)."

ATTACHMENT 2

NDIS Quality and Safeguards Commission, The NDIS Code of Conduct, Guidance for NDIS Providers March 2019 states that groups bound by the code must:

1. Act with respect for individual rights to freedom of expression, self-determination and decision-making in accordance with applicable laws and conventions
 12. People with disability have the right to make their own decisions, to be free to live the life they choose, and to have the same rights and freedoms as any other member of the community.
 13. A complex range of intersecting factors including individual and social values, contexts, cultures, policy responses, and histories, shape how individuals understand disability. In the past, a focus on a person's incapacity or the 'tragedy' of their disability portrayed them as dependent, helpless, and in need of care and protection. This often resulted in their isolation, segregation and exclusion from the wider community. It is now understood that people with disability have full and equal human rights.
 14. These rights are set out in the United Nations Convention on the Rights of Persons with Disability. They include the right to freedom of expression and the right to make decisions about, and exercise control over, their own lives. Choice and control is a core principle of the NDIS. People with disability have the right to choice and control about who supports them and how their supports and services are delivered.[9]
4. Act with integrity, honesty and transparency
49. Integrity, honesty and transparency are crucial to developing the trust-based relationships between people with disability, NDIS providers and workers that are required for high-quality service delivery.
 50. For clients to be informed consumers they need accurate information about their service providers, the services they receive, and any real or perceived conflicts of interest of the people working with them; and they should be able to make decisions in their best interest, free from inducements or pressure.
 51. Consistent with this element of the Code, factors that may be relevant when assessing if conduct complies with this element of the Code include (but are not limited to) a provider's actions to:

Recommend and provide supports and services appropriate to the needs of the participant affiliations of their workforce including if a worker has been excluded from an NDIS worker screening check for a role that involves more than incidental contact with people with disability.

- b. not make false claims about the efficacy of any supports, services or products.
- c. give clear advice about the full costs of the service or support and what the cost covers.
- d. not make claims about the efficacy of treatments or supports that cannot be substantiated independently.'

The Code of Conduct clause 55, covers the requirement to maintain integrity by declaring and avoiding any real or perceived conflict of interest.

52. People with disability have a right to accurate, accessible and timely information about the cost and efficacy of supports and services. This information may include: a clear quote for a service or support; easily understood breakdown of costs for different service options; information supporting the effectiveness of supports; the experience of other people with the service or support, and the risks and benefits of service options.
53. NDIS providers have a responsibility to only recommend and provide supports and services that are appropriate to the needs of the participant.
54. Under this obligation, NDIS providers should:
 - a. supply truthful information about the capacity, qualifications, training and professional

55. NDIS providers should disclose to the people with disability they support or who are seeking support, any conflicts of interest – potential or real – that may impact on how they deliver supports and services to that person. This would include conflicts of a financial, business or personal nature, including any financial and/or corporate interest or relationship the NDIS provider may have with other entities, including businesses and organisations, or of a personal nature, including but not limited to cultural, religious or social relationships.

56. An NDIS provider should:

Code of Conduct Clauses 59 and 60 define and prohibit the use of 'sharp practices'

'59. The term 'sharp practices' refers to a range of practices involving unfair treatment or taking advantage of people, including over-servicing, high pressure sales and inducements. Some sharp practices may undermine the integrity of NDIS providers, workers and/or the NDIS sector as a whole. Although not necessarily unlawful, sharp practices are considered unethical, dishonest and not in the interests of people with disability.

60. People with disability expect that NDIS providers will not participate in or promote sharp practices. This includes not:

- a. providing services or expending funds contrary to a person with disability's approved plan
- b. asking for or accepting any additional fees for providing the service
- c. offering inducements or rewards that have no particular link to a person's NDIS plan and that could be perceived to encourage people to take up or continue with your organisation or a particular service option
- d. engaging in high-pressure sales.

61. NDIS providers also need to ensure their workers are aware of their obligations not to participate in sharp practices.

62. Some unethical practices, such as misleading or deceptive conduct, and coercive or exploitative conduct, as well as being a potential breach of this element of the Code, may also be a breach of the laws and regulations administered by other regulatory authorities.

112. The NDIS Commission will gather, integrate and assess information about sharp practices from multiple sources, including workers, NDIS provider registration data, participant feedback and complaints, reportable incidents, referrals and intelligence from other agencies including the NDIA, and from its own market studies.'

- a. not give, ask for, or accept any inducement or gift that impacts or may impact on the way it provides supports or services under the NDIS, including any referral arrangements with other providers.
- b. not allow any financial or commercial interest in an organisation or company providing products, services or supports to people with disability to adversely affect the way in which the NDIS provider engages with people with disability.
- c. engage in recruitment practices, such as probity checks and reference checks, to uncover any potential or real conflicts of interest of people that it is considering employing.

57. Additionally, NDIS providers should ensure their workers:

- a. are aware of their obligation to declare a conflict of interest and inform people with disability when they have an interest that may impact supports and services provided to a person with disability (i.e. other than simply being paid for providing the services or supports);
- b. do not give inducements or gifts, ask for any inducement or gift, or accept any inducement or gift of more than minor value, from people with disability, their families, carers or advocates.

58. NDIS providers should also have internal policies and guidance for workers to follow for declaring and avoiding conflicts of interest and accepting and giving gifts.



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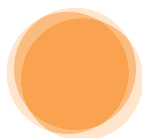
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