

# SUMMER FOUNDATION BRIEFING PAPER

## YOUNG PEOPLE IN RESIDENTIAL AGED CARE AND THE ROYAL COMMISSION INTO AGED CARE

SEPTEMBER 2018

It has long been established that residential aged care (RAC) is not the right setting for people under the age of 65 years. Young people with disability living in RAC are one of the most marginalised and isolated groups of people in our society. Fifty three per cent of young people in RAC receive a visit from a friend less than once a year and 82% seldom or never visit their friends.<sup>1</sup> They generally lead impoverished lives, characterised by loneliness and boredom. They are effectively excluded from society with 45% seldom or never participating in leisure activities in the community.<sup>2</sup>

### 1. THE ROYAL COMMISSION INTO AGED CARE

The Australian Government has announced the establishment a Royal Commission into Aged Care.

The Royal Commission will look at the quality of care provided in residential and home aged care to senior Australians. Young Australians with disabilities interacting with the aged care system have also been identified as a priority group.

The Summer Foundation wholeheartedly welcomes the Royal Commission. For young Australians, the Royal Commission should be squarely focused on stopping young people entering aged care.

“This Royal Commission should not re-open the question of whether aged care is the right place for young people with disability. In Australia, we have a consensus that the disability system is far better placed than the aged care system to support young people with disability.

The Royal Commission should focus on ensuring the disability, health and housing systems deliver the range of alternatives to RAC that will keep young people with disability out of aged care, rather than simply focusing on making aged care better for young people.”

– Luke Bo’sher, CEO of the Summer Foundation.

1. Winkler, D., Sloan, S. & Callaway, L. (2007), Younger people in residential aged care: Support needs, preferences and future direction, (Melbourne, Victoria: Summer Foundation). PDF

2. Ibid.

## Is a Royal Commission needed?

Yes.

The problem of young people entering aged care has been intractable over the past decade. A Royal Commission has the opportunity to cut through and bring about a solution to this complex problem.

Many younger people experience unacceptable outcomes in aged care. Fifty three per cent of young people in RAC receive a visit from a friend less than once a year and 82% seldom or never visit their friends.<sup>3</sup> Too many younger people in aged care lead impoverished lives, characterised by loneliness and boredom. They are effectively excluded from society with 45% seldom or never participating in leisure activities in the community.<sup>4</sup>

Despite the promise of the NDIS, too many young people are still entering aged care. In some of the areas where the NDIS has been rolled out for the longest time there are more young people entering aged care than before the NDIS began.

In Victoria's Barwon region, there has been an 80% spike in the number of young people using aged care for respite. Across Victoria we have seen 40% growth in the number of young people getting community aged care packages. These big increases are plugging gaps that the NDIS or health system need to be able to fill.

## How do we set up the Royal Commission to solve this issue?

There are two key decisions the government can make in the establishment of the Royal Commission that will set it up for success:

### **1. Ensure the terms of reference include preventing young people from entering aged care.**

A Royal Commission that focuses only on making aged care a better place for young people will be a missed opportunity. Ultimately, nothing we do can make aged care the best place for young people. Instead, the Royal Commission should direct its energy towards getting the settings right to give young people better options to avoid aged care.

### **2. Ensure young people have the support they need to participate in the Royal Commission.**

Young people in aged care are often very isolated from the community. Many don't have the support from family and friends to participate in complex government processes. Some will be afraid of speaking out against their providers. Government needs to ensure all young people in aged care are supported to tell their story to the Royal Commission.

We strongly encourage the government to keep the terms of reference broad to include preventing young people from entering aged care, and make sure resources are allocated to support young people to participate in the process.

3. Winkler, D., Sloan, S. & Callaway, L. (2007), Younger people in residential aged care: Support needs, preferences and future direction, (Melbourne, Victoria: Summer Foundation). PDF

4. Ibid.

## 2. THE GOVERNMENT'S POLICY ON YOUNG PEOPLE IN AGED CARE

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.<sup>5</sup>

COAG acknowledges that aged care services are not designed to meet the needs of younger people with disability and states that younger people should have access to disability specific accommodation and support services as these, rather than aged care services, are the most appropriate to their needs.

### **COAG principles:**

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.

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 specialist disability accommodation and support services that are appropriate to their needs.<sup>6</sup>

The COAG agreement further states that young people in aged care will receive enhanced specialist disability accommodation services to provide them with 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 their wellbeing while in RAC.

### **How are governments performing against this policy?**

The COAG agreement has not been matched by action on the ground to resolve the issue.

Every week 50 young people enter an aged care facility. This number remains similar to the number of young people entering aged care over 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".<sup>7</sup>

Success has been 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 five-year YPIRAC program, providing \$244 million. Summer Foundation's evaluation of the Victorian Government's element of this initiative has achieved a net reduction of 88 people (40%) between 2006-2011.<sup>8</sup>

A lack of ongoing investment and focus on this issue by governments has seen these numbers climb back to the original levels.

5. National Guiding Principles for the Referral and Assessment of Younger People with Disability, Australian Government Department of Health and Ageing, July 2008

6. National Guiding Principles for the Referral and Assessment of Younger People with Disability, Australian Government Department of Health and Ageing, July 2008

7. National Guiding Principles for the Referral and Assessment of Younger People with Disability, Australian Government Department of Health and Ageing, July 2008

8. <https://www.summerfoundation.org.au/wp-content/uploads/quality-of-life-evaluation-2012.pdf>

### 3. THE NDIS AND YOUNG PEOPLE IN AGED CARE IN AUSTRALIA

The NDIS has the potential to stop young people being forced into RAC. However, younger people are facing significant barriers to accessing the NDIS.

At end June 2018, 2,531 YPIRAC were active NDIS participants.<sup>9</sup> The majority of YPIRAC (3,712) are not yet NDIS participants.

Summer Foundation's NDIS Report Card looks at the performance of the NDIS twice each year. The June 2018 Report Card found that:

- **Aged care admissions are reducing in some areas, but increasing in others.**

Admissions of young people to residential aged care have reduced by 5 per cent across the trial sites of Hunter, ACT and Barwon.

The results are best in the ACT, which achieved a reduction in admissions of 30 per cent, and in the Hunter region of NSW admissions were down 17 per cent.

In Barwon, Victoria, admissions have actually risen by 37 per cent. A lack of suitable housing in Barwon could be a reason for the rise.

- **The NDIA was slow to get young people in aged care into the scheme, but this is picking up.**

As at 30 December 2017, only half as many young people in RAC had become NDIS participants as governments had predicted.

A focused effort by the NDIA to target young people in aged care saw an extra 1,109 people added to the scheme between September 2017 and March 2018. Almost as many young people in aged care came into the scheme in these 6 months as the previous 4 years.

However, another 118 young people living in RAC were found to be ineligible due to their disability not qualifying for the NDIS. This equates to one in 20 of those that were assessed being refused entry to the scheme.

- **Young people aren't getting enough funding in their NDIS plans to leave aged care.**

Only 23 of the 2,600 young people in aged care have funding for disability accommodation in their NDIS plans.

This means that 1.5% of NDIS participants living in residential aged care currently have enough NDIS funding to be able to leave their aged care facility.

98% of young people in aged care would need to ask the NDIS to undertake a review of their funding in order to get out of aged care.

#### Why hasn't the NDIS solved this problem?

The NDIS has an important role and there's more the NDIS could do to solve the problem. However the solution relies on the NDIS working in tandem with the housing and health systems.

Many young people in aged care do not know about the NDIS or have the support that they need to apply to become participants. For those who are deemed eligible, many face serious challenges developing and implementing their NDIS plans.

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9. COAG Quarterly Report Q4, July 2018

The problems experienced in planning include a lack of specialist disability accommodation (SDA) funding, insufficient funding for equipment and support, and a lack of expertise among planners and support coordinators working with people who have high and complex support needs.

Total plan funding for YPIRAC for all NDIS supports is low (average plan funding is \$105,000, of which over \$80,000 will go to the RAC as provider reimbursement).<sup>10</sup>

There is also a widening gap between what the health system provides and what the NDIS is delivering. This means that not all the person's support needs are being met through their NDIS plan, however key additional needs (e.g. nursing and clinical supports) are also no longer being provided by the health system.

The 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. Improving the range and scale of community-based housing and support will reduce the flow of young people into RAC, leading to better outcomes for young people with disability and lower costs for governments. It is critical the NDIS funding to increase these options is well targeted to create the diversity of housing options that young people with disability require.

Finally, when living in the community, people with high and complex disabilities can experience barriers to accessing the high quality primary health services they need. As a result, many are forced to return frequently to hospital when their health needs multiply, increasing their likelihood of being forced into RAC.

## 4. DATA ON YOUNG PEOPLE IN RAC

In the 10 years since the COAG agreement, there has been limited progress in reducing the number of younger people with complex needs being admitted to RAC, and in increasing the rate of younger people leaving RAC to live in the community.

- As at June 30 2017, there were 6,242 YPIRAC across Australia.<sup>11</sup> In 2007-2008 this number was 6,609, however after an initial reduction, the total has stayed relatively constant since 2013-2014 (6,288) to 2016-2017 (6,243).<sup>12</sup>
- Over 2,660 people under the age of 65 entered aged care in 2016-2017.<sup>13</sup>

### Number of permanent residents in aged care, by age and state/territory, at 30 June 2017

Age	NSW	VIC	QLD	WA	SA	TAS	ACT	NT	Australia
0-49	189	170	111	29	28	12	1	2	542
50-64	2,062	1,457	1,125	441	387	135	43	50	5,700
Total	2,251	1,627	1,236	470	415	147	44	52	6,242

10. Senate Estimates

11. George Taleporos, "Five years on, NDIS is getting young people out of aged care, but all too slowly", The Conversation, Jun 12, 2018, <https://theconversation.com/five-years-on-ndis-is-getting-young-people-out-of-aged-care-but-all-too-slowly-97851>.

12. Report on Government Services 2018. Table 15A.54

13. Australian Institute of Health and Welfare (2017) Customised Data Request - Younger People in Residential Aged Care, Table 4.

- The overwhelming majority (90%) of young people in aged care currently have a partner, or had a partner before entering aged care.
- The large number of young people separated and divorced in aged care is partly driven by the aged care model preventing families from maintaining their relationships.

<b>Marital status (Australia)</b>	<b>Number</b>	<b>Percentage</b>
Married/de facto	292	5%
Previous partner (widowed, separated, divorced)	5,307	85%
Never married	470	8%
Unknown	176	3%
<b>Total</b>	<b>6,245</b>	<b>100%</b>

- Of the young people who leave aged care just one in 10 leaves to return home, while more than half only leave aged care through death.

<b>Reason for separation from aged care (Australia)</b>	<b>Number</b>	<b>Percentage</b>
Death	1,007	56%
Hospital	120	7%
Other residential care	327	18%
Return to family or home	202	11%
Other	155	9%
<b>Total</b>	<b>1,811</b>	<b>100%</b>

- There is a lack of data on key areas that are needed for monitoring lack of progress on processes such as achievement of SDA funding for YPIRAC. The NDIA is currently unable to supply data on the number of YPIRAC who became NDIS participants while in RAC, and have since left RAC. There is also a significant gap in data on the number of new dwellings for people with disability created by the NDIS.

## 5. HOW WE CAN STOP YOUNG PEOPLE FROM BEING FORCED INTO AGED CARE?

We know how to solve this problem. Systemic change is needed across 4 key areas:

### Housing

The lack of timely access to the housing and support people need to live in the community is one of the key reasons young people live in RAC.

Improving the range and scale of community based housing and support is needed to reduce the flow of young people into RAC, leading to better outcomes for young people with disability and lower costs for governments.

It is critical the NDIS funding to increase these options is well targeted to create the diversity of housing options that young people with disability require.

To fix this problem we need:

- Housing to be accessible and in locations that build community connections
- Housing choices to be diverse and support changes in circumstances and preferences over time, including options that support families to live together
- Investors in housing to have confidence in the structure and delivery of the NDIA's housing payment scheme
- The design and delivery of housing and support models to be innovative and highly collaborative

### NDIS

The NDIS is not yet meeting the needs of young people in RAC or sufficiently stopping the flow of young people into RAC.

Young people in RAC are facing significant barriers to accessing the NDIS. Some young people in RAC are isolated from informal support networks and many never had interactions with the disability system before entering RAC. This means they often do not know how to go about applying for support from the NDIS.

To fix this problem we need:

- NDIS systems and processes to ensure young people in RAC have a rapid and streamlined entry into the scheme
- Participants' right to choice and control to be upheld by the scheme, including sufficient funding to live independently in the community and access the necessary housing or home modifications
- Service providers to have the expertise necessary to support people with high or complex support needs

## Hospital discharge pathways and the NDIS/health interface

Successful discharge planning for a smooth and timely transition back into the community for people with complex support needs now requires skills and understanding of the NDIS pathway. When there is no immediate pathway home, many young people are forced into RAC leading to poor health outcomes and isolation from family and friends.

The NDIS and health systems do not currently work together in a streamlined way to ensure people with disability have the right support at the right time. Those responsible for discharge planning sometimes lack the necessary expertise or resourcing to support people back into the community in a timely way.

To fix this problem we need:

- Those eligible in the health system to be registered with the NDIS promptly, flagged and have their NDIS planning fast tracked
- Discharge planning for young people with complex needs to commence early after their admission and to be undertaken by a skilled practitioner
- Transitional and flexible accommodation options available as an alternative to aged care for being discharged from hospital, especially while waiting for home modifications or long-term suitable housing
- For existing NDIS participants, potential need for an NDIS plan review based on change of circumstances to be flagged with the NDIA resulting in a coordinated, timely response

## Primary and community health

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.

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 healthcare to be available and responsive to people with disabilities with high and complex needs

## 6. HEARING DIRECTLY FROM YOUNG PEOPLE

### Case study 1

**Since the NDIS trial commenced on 1 July 2013 and up until 30 June 2017, the number of younger people admitted to RAC in Barwon increased by 37%.**

Charlie\* is a 54-year old man who lived on his own in a rented flat prior to a fall that resulted in a spinal cord injury. Charlie spent the next six months in hospital and rehabilitation. He resigned from his job, ended the lease on his flat and packed up his life.

A social worker at the rehabilitation unit finalised Charlie's NDIS paperwork and helped him search for appropriate accessible housing. When no suitable housing could be found, Charlie was discharged into a residential aged care facility.

Charlie's access to physiotherapy paused when he entered the nursing home, and he feels that he went backwards at a critical time in his rehabilitation journey. Charlie moved nursing homes in search of better care.

Issues around signing off on his equipment, between the NDIS and the equipment provider, mean that he still relies on a rented wheelchair and shower commode. Charlie also had problems with his NDIS appointed support coordinator, which means he still can't access the NDIS portal.

Implementation of the NDIS remains a challenge and young people are still entering registered aged care.

"My social worker was looking for disability accommodation and there was nothing in the Barwon region. ...and then there's the issue that it would have to suit me as well. I would want to consider carefully who I'd be sharing with.

It's funny because there are new aged care facilities going up all over Barwon, I know we have an ageing population, but there are lots of people with disabilities. How about some specialist disability accommodation?" – Charlie

## Case study 2

### The NDIS can keep young people out of aged care, but NDIS solutions are not routinely system driven.

Sam\* was 27 years old and had moved out of home. He had a partner and a very active social life. Sam also had a burgeoning career in project management and was very ambitious. After an accident resulting in an acquired brain injury, Sam spent eight months in hospital and then, in a minimally conscious state, entered rehabilitation.

During the time in rehabilitation Sam made excellent progress by learning to walk, talk and eat again. Sam's rehabilitation progressed further to the point he was able to attend to his personal care independently, fix basic meals and walk to the gym.

Sam was told by the rehabilitation service that the options for discharge were limited to either residential aged care or returning to the family home. Sam's family wanted Sam to be able to live as independently as possible and believed that neither option offered was appropriate for a young person.

The discharge team had little NDIS knowledge. They actively discouraged Sam's family from applying for NDIS funding on the basis that the family home was 'out of region'. Sam's family advocated strongly for Sam - they lobbied the local MP with a petition for early NDIS funding and they took Sam's story to the media.

A week after media exposure, Sam was granted early access to NDIS funding.

For Sam, a solution came, not through a system driven solution, but through Sam's family's unrelenting advocacy forcing a system outcome.

"We are where we are today as a result of our advocacy, not as a result of what the NDIS or the health system did to support us." - Sam's sister Anna

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## ABOUT THE SUMMER FOUNDATION

The Summer Foundation 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 will have access to services and housing that support their health and wellbeing and a good life in the community.

We are committed to working with key stakeholders to achieve accessible and affordable supports for young people with disability with complex support needs, to enable them to choose where, and with whom they live. We are committed to working to ensure that the NDIS realises its potential to end the forced admission of young people with disability into nursing homes. Please visit our website to learn more about the issue of Young People in Residential Aged Care.



[summerfoundation.org.au/holding-out-hope](https://summerfoundation.org.au/holding-out-hope)



[summerfoundation.org.au/kates-story](https://summerfoundation.org.au/kates-story)



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