Improving Outcomes for Younger People in Residential Aged Care



March 2023

Younger people with disability do not belong in residential aged care (RAC). The aged care sector is set up to deliver end-of-life supports and comfort.

A younger person (under the age of 65) with complex disability needs highly specialised support, which is vastly different to the needs of an older person.

Inappropriately placing younger people with disability into RAC isolates them from family and friends, and inhibits their capacity for independence and community participation. They lose skills and capability and are not able to have choice over their lives.

What is the problem?

Younger people are still entering RAC

Although there has been a decrease in the number of younger people entering RAC over the past 2 years, 497 people under 65 entered aged care in the last financial year. Previous government initiatives attempted to solve the problem of younger people in residential aged care (YPIRAC) but did not create the systemic change needed to deliver better outcomes.

Instead of going to RAC, younger people with disability are getting stuck in hospital for months or even years.²

Lack of housing for people with disability is not the main barrier to accessing age-appropriate housing. There are 3,000 vacancies in disability housing across Australia, 1,000 of which are in new build Specialist Disability Accommodation (SDA).³ Younger people with disability need timely and skilled support to transition out of hospital into appropriate housing.

Younger people are not moving out of RAC

In the 2022 financial year only 39 young people moved out of RAC into SDA. An estimated 2,000 YPIRAC who do not have a goal to move need independent, expert and patient support to explore options and make an informed decision about where they live.

There are currently 2,934 younger people with a disability living in RAC. Few YPIRAC move out to live in better housing options. Most either stay in RAC until they turn 65 or die in RAC. Around 80% of YPIRAC are NDIS participants and an estimated 95% are likely to be eligible for the NDIS. Currently only 26% of participants in RAC have a goal to move.

¹ Current as at 30 June 2022. See: Australian Institute of Health and Welfare 'Younger people in residential aged care'. Link here.

² Cubis L, Ramme R A, Roseingrave E, Minter E, Winkler D and Douglas J (2022) 'Evaluating the discharge planning process: Barriers, challenges, and facilitators of timely and effective discharge for people with disability and complex needs' Summer Foundation and La Trobe University. Link here.

³ Housing Hub website.

What does success look like?

By January 2025:

- Every YPIRAC is supported to make informed decisions: The 2,934 young people currently in RAC have all received expert, patient and independent support to build their capacity and confidence, explore housing options and make an informed decision about moving out.
- **No new entries to RAC:** Younger people at risk of entering RAC have received independent skilled support to navigate and secure the timely disability, health and housing services they need to leave hospital and avoid RAC.
- Timely funding decisions: The National Disability Insurance Agency (NDIA)
 routinely makes decisions about funding for housing and support for participants
 in and at risk of entering RAC within 10 days.

Solutions that will ensure good outcomes

For all younger people in and at risk of entering RAC

Supporting a younger person to understand what a life could be like outside of an institutional setting requires extensive capacity building and guidance.⁴ Choosing where to live is a big decision and navigating the options under the NDIS is complex. There is currently inadequate support and information for participants to make an informed decision.

The <u>Summer Foundation</u> is uniquely placed to partner with the Federal Government to deliver outcomes for YPIRAC because of its track record. The Summer Foundation has:

- Supported more than 750 participants, including 100 YPIRAC, to navigate the NDIS and find new homes
- Co-designed more than 20 resources to build the capacity of NDIS participants to make an informed choice about housing and support and move
- Delivered <u>UpSkill</u> support coordination training to 2,183 attendees
- Published more than 40 peer reviewed journals and is the leading international expert and thought leader on YPIRAC and alternative housing options
- More than 1,500 disability housing providers listing both SDA and non-SDA vacancies on the <u>Housing Hub</u>

For NDIS participants

YPIRAC Exit Demonstration Project

Younger people in and at risk of entering RAC should be supported by independent Transition Navigators who are experts in disability, health and housing. Transition Navigators

⁴ Summer Foundation (2021) 'Storytellers with lived experience strengthening opportunities for people with disability to live independently'. Link <u>here</u>.

will work alongside younger people to navigate the NDIS and aged care system, build their capacity, explore housing and support options and transition to living well in the community.

Hospital Exit Demonstration Project

To prevent new entrants to RAC, NDIS participants will be supported to move from hospital to the best available disability housing that matches their needs and preferences. Ongoing support will build the capacity, confidence and independence of participants to make an informed decision about longer term housing.

Transition Navigators and scaling

Every participant in, and at risk of entering RAC should have at least 40 hours of Level 3 Specialist Support Coordination funding included in their NDIS plan to safely transition out of, or prevent entry to, RAC. Transition Navigators can be funded through this NDIS line item. Transition Navigators will work with participants for a limited time and step away once the participant has transitioned into housing with the right supports. Scaling this workforce will also involve creating an online directory of Transition Navigators with a track record of effectively supporting participants to navigate housing options.

Housing demand data for YPIRAC and young people at risk of RAC

Data on the housing needs and preferences of YPIRAC is needed to inform timely and effective responses. The Summer Foundation will collaborate with Transition Navigators to collate and publish SDA market data specific to the housing and support needs and preferences of YPIRAC and NDIS participants in hospital. This will enable SDA providers and state governments to build housing for current and future unmet demand.

For younger people who are not eligible for the NDIS

State and territory governments need to step up and provide housing and health services to the 5% of YPIRAC who are not eligible for the NDIS. The NDIA holds data on the housing and support needs of participants who are not eligible for SDA. This should be shared with state and territory governments to enable the development of accessible non-SDA housing, particularly social and public housing. This will also increase housing options for participants who are not eligible for SDA.

State and territory governments must be equipped to monitor the impact of the NDIS and obtain an evidence base about how mainstream systems can better meet the needs of all people with disability over time. The needs, preferences and experiences of people with disability must be better understood to enable the market to provide innovative responses that meet the needs of younger people in and at risk of entering RAC.

United Nations Convention on the Rights of People with Disability

Appropriate housing is a human right enshrined in the <u>United Nations Convention on the Rights of Persons with Disabilities</u> (UNCRPD). By ratifying the UNCRPD, Australia recognises the equal right of all people with disability to live in the community, with choices equal to others.⁵ The Federal Government must take effective and appropriate measures so people with disability can realise their right to full inclusion and participation in society.

⁵ See Article 19 of the UNCRPD.