

Younger people living in, or at risk of entering residential aged care who are not NDIS participants: Towards living a better life

Dr Caroline Hart, Dr Stella Koritsas, Dr Barrie Shannon and Prof Keith McVilly – January 2023

Summary of results

Background

This research explored the experiences of younger people (under the age of 65 years) who were living in, or at risk of entering residential aged care (RAC). The focus of the research was on younger people who were not NDIS participants because there is very little previous research on this group.

The aim of the research was to identify what helped and hindered younger people who are not NDIS participants from leaving or avoiding RAC, and the reasons why some choose to stay in RAC. Views and experiences of the Ability First Australia System Coordinator Program (the Program) were also explored. This Program is nationally funded and aims to help younger people access appropriate services and supports to either move out of or avoid entering RAC.

What did we do?

Data was collected using surveys, interviews and focus groups with the following people:





- ✓ **Younger people** living in, or at risk of entering RAC
- ✓ **Key contacts** and **family members**
- ✓ **Program staff**
- ✓ **Stakeholders** from health, aged care, housing, disability and advocacy

Data collected by the Program staff as a part of their day-to-day work (for example, younger people's goals and the actions taken to help achieve those goals) was also analysed.





What did we find?

Many younger people who were living in, or at risk of entering RAC and were not NDIS participants had complex/ multiple medical conditions, or life-limiting illnesses/ palliative care needs. They often required 24-hour support. Although some younger people reported that they were happy in RAC, overall, their wellbeing and community engagement was much lower than the general population.




Things that **helped** younger people leave or avoid RAC included:

-  Access to funding for services and appropriate housing
-  Having help to explore alternative options and navigate funding and services
-  Collaboration across services and sectors
-  Family support

Things that **hindered** younger people leaving or avoiding RAC included:

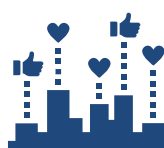
-  A lack of funding to live elsewhere in the community
-  A lack of appropriate housing
-  Difficulties navigating funding and services
-  Hospital discharge and referral processes

There were significant **gaps** in:

-  Services for younger people with life-limiting illnesses or palliative care needs
-  Services and housing in rural, regional and remote areas
-  Transitional programs and housing



Younger people choose to remain in RAC because they feel **safe, secure, and well cared for**.



There is a lack of funding to provide the **same level of care** that is available in RAC.

Views and experiences of the Program

- ✓ Younger people and family members felt more informed about the alternative living options available to them.
- ✓ Program staff reported that spending time and engaging with younger people worked well and empowered younger people.
- ✓ Stakeholders reported that the Program was interrupting the traditional hospital-to-RAC pathway.
- ✓ More information about the work and goals of the Program was needed for younger people, their key contacts and the services involved in supporting them.



Long-term case management was important when working with younger people.



Building rapport and establishing trust was important when working with younger people.



Providing information about alternative options was important when working with younger people.

What are the implications?

This research was presented in a report to the Department of Health and Aged Care. The report makes several important recommendations about policy and practice. These include:

Ongoing data collection to capture the characteristics and circumstances of younger people who are not NDIS participants living in, or at risk of entering RAC.

Increased funding for the full range of services that younger people who are not NDIS participants need to leave or avoid RAC (including for palliative care, and services in rural, regional, and remote areas).

Simplification of processes for accessing funding, including timely and transparent decision-making about eligibility.

Regulatory alignment of disability and aged care sectors to address dual compliance issues.

Investment in affordable and accessible housing and the development of innovative housing models for younger people who are not NDIS participants.

Ongoing collaboration across government departments and sectors to address service fragmentation.

Support for younger people to make decisions and training about decision-making for everyone involved in younger people's care.

Improved access to transitional programs and rehabilitation services.

Continued provision of long-term, complex case management for younger people who are not NDIS participants through initiatives such as the Program.

Increased promotion about the work and aims of the Program to assist its work with younger people.

Who can I contact for more information?

Contact the researchers at Scope:
research@scopeaust.org.au

In collaboration

