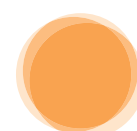


POSITION STATEMENT

OCTOBER 2016

ACCESS TO THE NDIS FOR YOUNGER PEOPLE IN RESIDENTIAL AGED CARE



**SUMMER
FOUNDATION**

KEY MESSAGES

- Around 6,200 young people aged under 65 years are living in residential aged care (RAC). These young people experience extreme social isolation with 44% receiving a visit from family or friends less than once per year.
- The most common reason for young people to enter RAC is that the disability system has failed them through inadequate levels of support or services that do not meet their needs.
- The NDIS presents a significant opportunity to assist young people to exit RAC and to reduce new entries into RAC. Our evidence suggests that almost all young people in RAC will be eligible for the NDIS.
- The NDIS should meet the following criteria to fully support young people in RAC:
 - Young people in RAC are engaged in the Scheme through active outreach and a streamlined access process
 - Young people understand the NDIS planning process and how to construct a goal, and know their goals and support needs before agreeing an NDIS plan
 - Young people who require support to make decisions are provided with sufficient time and assistance to make informed decisions
 - Young people at risk of RAC entry are supported by a 'whatever it takes' attitude by the NDIS to prevent entry into RAC.
- The NDIS has the right building blocks in place to support all young people in RAC through a:
 - Guaranteed package to meet the 'reasonable and necessary' needs of all eligible young people in RAC;
 - Person-centered planning approach; and
 - Flexible package that changes as people's needs change.
- There are five actions we recommend the NDIS undertakes to ensure it lives up to its ambition of fully supporting young people in RAC:

Recommendation 1: The core NDIS operating model must include dedicated outreach to young people in RAC during the full scheme roll out.

Recommendation 2: Young people in nursing homes should be generally considered to meet the disability requirements, and should not need to provide further evidence of their disability.

Recommendation 3: NDIS funding should include supported decision-making and provide young people with continuity of assistance from eligibility assessment through to goal identification and plan implementation.

Recommendation 4: As part of a mainstream strategy with the aged care system, data should be shared nationally on the RAC facilities where young people are living to ensure information about the NDIS reaches young people, their families and RAC staff.

Recommendation 5: In all locations where the NDIS is operating, young people at risk of RAC entry should be supported to immediately make an access request and, if eligible, have access to funded supports that prevent RAC entry. Effective hospital liaison positions need to be in place as a key building block.

1. BACKGROUND

Currently over 6,200 people under 65 years live in residential aged care (RAC) nationally, most often with acquired / late onset neurological impairment (89%)^{1,2}. In addition, there are nearly 200 people under 50 at risk of admission to aged care each year in Australia.³

RAC does not enable young people to achieve their potential or lead fulfilling lives. Young people in RAC experience extreme social isolation with 44% receiving a visit from family or friends less than once per year, 34% never participating in community activities and 21% leaving the home less than once per month.⁴

This social isolation occurs despite many young people in RAC leading highly connected lives prior to entry in RAC. Many (46%) young people in RAC are in partner relationships and 27% are parents of school-aged children.⁵

RAC separates young people from their community, family, friends, partners and children. Young people with disability should have the ability to live in a home that meets their needs and allows them to actively participate in the community, and to build and maintain relationships with family and friends.

The NDIS has the potential to be the single largest improvement to the lives of young people in RAC, enabling many young people to leave RAC and live in more age appropriate settings.

PREVIOUS ATTEMPTS TO ASSIST YOUNG PEOPLE IN RAC

The five-year, \$244M national Young People in Residential Aged Care (YPIRAC) Initiative (2006-2011) provided targeted support to young people aged under 50 years living in RAC, and to those at risk of entry into RAC.

This initiative made a significant difference to the lives of the people who received services. 250 people were assisted to move out of RAC and a further 244 people avoided being admitted to RAC.

The YPIRAC program was funded through a fixed pool of funds that was unable to meet the needs of the majority of young people in RAC.^{6,7} More than half of young people in RAC (56%) did not participate in the YPIRAC program, with the 62% of those under 50 not receiving any additional support through YPIRAC.⁸

Despite the YPIRAC initiative being driven by the Council of Australian Governments (CoAG) as a key priority, YPIRAC has not led to a systematic change to reduce the entry of young people into aged care. The number of people aged under 50 entering aged care has reduced only marginally from 235 people in 2006-07, to 196 in 2014-15.⁹

Lessons from the YPIRAC experience should inform future attempts to improve the lives of young people in RAC. One of the primary limitations of YPIRAC was that it did not pro-actively engage with young people in RAC through face-to-face visits. Rather, it relied on people with disability responding to written letters inviting them to participate in the initiative. In the absence of any follow up directly with young people, many young people missed out on the opportunity to access this support.

THE ROLE OF THE NDIS IN ASSISTING YOUNG PEOPLE IN RAC

The NDIS was launched in seven trial sites across Australia from July 2013 and will be fully rolled out across all jurisdictions (except WA) by 1 July 2019. The Summer Foundation has been actively involved in four NDIS trial sites, connecting young people in RAC with the NDIS to ensure they have the opportunity to become participants in the Scheme and get the support they require.

The Summer Foundation has been supporting young people in aged care to make access requests to the NDIS. Through this project 98% of the young people we have supported have been accepted as eligible for the NDIS. When the NDIS is rolled out nationally, the Scheme is expected to cover all 6,200 young people in RAC.

Young people in RAC will comprise a small part of the 460,000 people with disability who will be in the NDIS. It is essential that the unique needs of this population group are met by the NDIS and not lost in the challenge of delivering this difficult reform.

2. A WELL FUNCTIONING NDIS FOR YOUNG PEOPLE IN RAC

The Summer Foundation has identified four core characteristics of the NDIS that must be operating effectively so that young people in RAC will fully benefit from this significant reform.

► **Effective NDIS Characteristic #1: Young people in RAC are identified and engaged in the Scheme through active outreach and a streamlined access process**

There must be active support that reaches out to young people in RAC to inform them about the NDIS, assisting them in making an application to the NDIS and supporting them through the NDIS planning process.

Many young people in RAC are not well connected to services outside the RAC facility and therefore may not find out about the NDIS or be assisted to connect with the NDIS. The Summer Foundation's work with young people in RAC in NDIS trial sites found that 75% were not connected to state-based disability services.¹⁰ Further, young people in RAC have limited informal support from family and friends with just 44% receiving a visit from family or friends less than once per year¹¹.

The YPIRAC initiative showed that getting young people out of aged care requires a dedicated outreach function that is able to meet in person with young people who are residing in aged care.¹² This is reinforced by our findings from the NDIS Connections projects in trial sites.

Given that almost all young people in RAC will be eligible for the NDIS, the eligibility process for these young people should not be onerous. Rather it should assume that young people in aged care meet the NDIS disability requirements. This is especially critical for young people in aged care because they often lack the informal support from family and friends necessary to compile evidence of disability, and complete extensive application documents required to become a participant in the NDIS.

► **Effective NDIS Characteristic #2: Young people who require support to make decisions are provided with sufficient time and assistance to make informed decisions**

Young people in residential aged care are a diverse group with different capacities to make decisions about their lives and varying levels of decision-making support from family, friend and formal guardianship arrangements.

An effective NDIS would ensure that all young people in RAC have the support they need to make decisions about their lives and their NDIS plan. The social isolation and skill depletion that occurs when living in RAC means young people in RAC frequently require additional supports to regain or establish basic skills in this area. Supported decision-making for these young people would occur in a framework that promotes independence and community connections.

This assistance would be provided by someone who operates exclusively in the person's interests, such as an advocate or a skilled disability or clinical provider who is not connected with a support provider.

► **Effective NDIS Characteristic #3: Before agreeing to an NDIS plan, young people understand the NDIS planning process and know their goals and support needs**

Many young people in RAC have experienced significant trauma, social isolation and skill depletion as a result of living in RAC. These young people will require time and support to develop their goals and aspirations.

The trauma of being separated from family and friends through having no appropriate living options may require intensive support to assist people to understand the NDIS planning process, to imagine their ideal living arrangement and to implement their plan. Without investing in support that helps young people in RAC to think about where they would like to live, how they would like to live and the support they need to achieve these goals, some younger people may choose to stay in RAC because they can no longer imagine another world.

The planning process should be the culmination of thorough plan preparation work, often involving the introduction of concrete examples that can assist young people and their families who struggle to conceive of any alternative to living in RAC.

► **Effective NDIS Characteristic #4: Young people at risk of RAC entry are supported by a 'whatever it takes' attitude by the NDIS to prevent entry into RAC**

Evidence on RAC placements consistently demonstrates that once a person enters RAC their life outcomes are significantly reduced and exiting RAC is highly challenging.¹³ An effective NDIS would do 'whatever it takes' to stop young people from inappropriately entering RAC in the first place. Most young people enter RAC directly from acute or rehabilitation wards in hospitals.

To effectively stop entry into RAC, the NDIS would coordinate with Aged Care Assessment Teams to identify young people who are applying for entry into RAC and intervene to offer all supports necessary to find alternative housing and support. The NDIS would also recognise that up-front investments in keeping young people out of RAC will reduce long-term financial costs for the NDIS and increase the quality of life for young people with disability and their families.

The Scheme should recognise the complexity of the interface across the Health, Aged Care and Housing sectors by ensuring adequate resources are put in place to reduce the likelihood of defaulting to the default option of entry to RAC.

3. THE CURRENT NDIS VERSUS A FULLY EFFECTIVE FUTURE NDIS

The basic building blocks of an effective NDIS for young people in RAC are being put in place, yet the NDIS is still changing and adapting to the lessons being learnt through the trial period. The Summer Foundation supports this approach to ensure the NDIS adapts over time to meet the changing needs of people with disability, and as the new market place for disability service provision is developed.

THE NDIS BUILDING BLOCKS ARE BEING PUT IN PLACE...

Three design features of the NDIS will provide enormous benefits for young people in RAC and those at risk of entering RAC, and position the NDIS to live up to the four characteristics we have outlined above.

1. **A guarantee of 'reasonable and necessary' support for all young people in RAC who meet the NDIS eligibility criteria.**

Packages of support will include assistance with personal care and life tasks in the home, home modifications and aids and equipment. This will overcome the barrier of insufficient or uncertain levels of support that stop young people from exiting RAC. For young people at risk of entering RAC, the NDIS will provide sufficient support for people to continue to live on their own or with their family, avoiding inappropriate entry into RAC. Further work is required to ensure that these packages meet the needs of young people in RAC in a timely way. The clinical care needs of these participants needs to be recognised and included in plans.

2. **A person-centred planning approach to meet participant goals and aspirations.**

Young people can be in RAC because their circumstances do not fit standardised packages of support that are available in the current disability system. The NDIS will build support around the individual goals and aspirations of young people in RAC.

3. **Flexible support packages that change over time, as people's needs change.**

Young people can be in RAC because their needs change over time and the supports available cannot meet their changing needs. NDIS packages are intended to be flexible, enabling people to purchase more support when they need it and less support when they are more independent. This aspect of choice and control for people with disability enable negotiations between participants and service providers so that service match people's needs.

...YET SIGNIFICANT CHALLENGES REMAIN

The NDIS building blocks may be in place, yet more refinement is required for the NDIS to fully meet the needs of young people in RAC.

Five areas of action require urgent attention to build an NDIS that lives up to the expectations for young people in RAC.

1. **Active outreach for young people in RAC to get access to the NDIS**

The early stage of the NDIS trial has shown that if young people in RAC are not supported to engage in the NDIS, they are unlikely to become participants in the NDIS.

The Summer Foundation's NDIS Connections program is providing assistance to young people in RAC, including outreach visits and assisting with eligibility and planning. Through this project, we have identified that only one quarter of young people in RAC are known to be connected to state-based disability services.¹⁴

When the Summer Foundation started seeking out young people in nursing home in the Barwon and Hunter NDIS sites, there were 234 people¹⁵ in nursing homes and we identified 155 who had not made an access request to become a participant. This suggests that the NDIA is reaching a low number of young people in nursing homes, leaving at least 66% missing out on the NDIS. However, the Summer Foundation's work in NDIS Connections is not a systematic part of the NDIS' operational design.

Recommendation 1: The core NDIS operating model must include dedicated outreach to young people in RAC during the full scheme roll out. Performance targets for Local Area Coordination (LAC) partners or funding a specialist LAC service would be ways to address this situation.

2. **Streamlining the process to become a participant in the NDIS**

The Summer Foundation's NDIS Connection project has found that 98% of young people in aged care are eligible for the NDIS. Despite this very high percentage of participants meeting the eligibility requirements, young people in nursing homes still have to provide evidence of their disability and account for their support needs before they can be considered for entry to the Scheme. This is a time consuming task that is difficult for young people who often have limited capacity themselves, or have limited support from family and friends.

The NDIS application process allows for people with disability already using some specific program to automatically meet the NDIS disability requirements. In Tasmania, being in aged care is one of these programs. This approach should be expanded across all NDIS sites in Australia to streamline access to the NDIS for young people in aged care.

Recommendation 2: Young people in nursing homes should generally be considered to meet the disability requirements, and should not need to provide further evidence of their disability.

3. **Assistance for young people to make informed decisions**

The Summer Foundation's work in RAC has shown that many young people require assistance with making decisions about their lives but are not connected to people or systems that help them to make decisions. In some cases, young people have highly impaired decision-making ability, with decisions about their lives being made by default by RAC staff.

The NDIS 'My First Plan' approach is an opportunity to support young people in RAC through faster plan development and approval. It will be critical to ensure that the "My First Plan" approach does actively listen to what young people in RAC require and provide funding to enable immediate access to reasonable and necessary aids and equipment, assistance to access social and community opportunities and housing 'Specialist Disability Accommodation' funding.

Young people need an independent support person who is focused on working in their best interest. This is an emerging gap in the current design of the NDIS. The NDIS expectation that people with disability have clear capacity themselves, have an appointed guardian or have natural supports does not hold true in all cases. Support to make decisions needs to be provided across a spectrum ranging from occasional assistance to discuss ideas and options through to formal guardianship arrangements.

The NDIS does not yet have a structure in place to ensure that young people get the support they need to make informed decisions. When young people do not have access to this decision-making assistance they risk being delayed in making an access request to NDIS and are at risk of developing an inadequate plan. Further, there is also a risk that young people will lack the confidence, information and support to make significant decisions about leaving RAC if they do not have an independent support person to help them understand and work through often challenging and complex decisions.

Recommendation 3: NDIS funding should include supported decision-making and provide young people with continuity of assistance from eligibility assessment through to goal identification and plan implementation.

4. **Data sharing to ensure that all young people in RAC can make an access request**

A majority of young people in RAC do not have any existing relationship with disability services. They are only getting supports through what is available in the aged care system, which is not well connected to the NDIS. Information about the Scheme is therefore unlikely to reach them.

The effectiveness of the Summer Foundation's NDIS Connections program was greatly increased through the sharing of Commonwealth aged care data to identify RAC facilities where young people were living in NDIS trial sites.

Through this work, the Summer Foundation found that there are discrepancies between the number of young people in aged care identified in the Commonwealth Department of Health's data and the experience of working with RAC facilities on the ground in NDIS trial sites.

Recommendation 4: As part of a mainstream strategy with the aged care system, data should be shared nationally on the RAC facilities where young people are living to ensure information about the NDIS reaches young people, their families and RAC staff.

5. **Expedited eligibility for young people at risk of RAC entry**

The NDIS staged roll out process means that people with disability become eligible at different times depending on where they live or the services they are accessing.

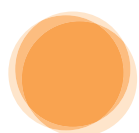
The NDIA should ensure that where entry to RAC is a likely outcome for a person with disability, the person is able to become an NDIS participant quickly and get the support they require to avoid an aged care placement. In any area where the NDIS is currently operating, the NDIA should not require people with disability to wait until a phasing date, rather they should get access to the Scheme through the 'new participant' category. The NDIA should be coordinating with Aged Care Assessment Teams to identify young people at risk of RAC entry and provide assistance through this expedited eligibility.

Funded supports to avoid RAC entry could include purchasing aids and equipment, allied health services, funding home modifications, respite services and assistance with personal care and life tasks in the home. Support coordination and recognition of the critical relationship with clinical supports should be recognised in all plans for young people in or leaving RAC.

Recommendation 5: In all locations where the NDIS is operating, young people at risk of RAC entry should be supported to immediately make an access request and, if eligible, have access to funded supports that prevent RAC entry. Effective hospital liaison positions need to be in place as a key building block.

REFERENCES

- ¹ Commonwealth of Australia. The Senate Community Affairs Reference Committee: *adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia, final report*. Canberra, Australia: Author; 2015.
- ² Winkler D, Holgate N, Sloan S, Callaway L. *The Victorian Younger People in Residential Aged Care Initiative: evaluation of quality of life outcomes for participants*. Melbourne, Australia: Summer Foundation Ltd; 2012.
- ³ AIHW National Aged Care Data Clearinghouse. *AIHW National Aged Care Data Clearinghouse Data Request: Younger people in RAC 2012-2013*. Canberra, Australia: Author; 2014.
- ⁴ Winkler, D. F., Farnworth, L. J., Sloan, S. M., & Brown, T. Young people in aged care: progress of the current national program. *Australian Health Review*, 35(3), 320-326; 2011.
- ⁵ Winkler D, Sloan S, Callaway L. *Younger people in residential aged care: Support needs, preferences and future directions*. Melbourne, VIC: Summer Foundation Ltd; 2007
- ⁶ Winkler D, Holgate N, Sloan S, Callaway L. *The Victorian Younger People in Residential Aged Care Initiative: evaluation of quality of life outcomes for participants*. Melbourne, Australia: Summer Foundation Ltd; 2012
- ⁷ Winkler D, Callaway L, Guthrie S. *National Disability Insurance Scheme launch sites: projection of the number of young people in residential aged care*. Melbourne, Australia: Summer Foundation Ltd & PwC; 2013.
- ⁸ Winkler D, Sloan S, Callaway L. *Younger people in residential aged care: Support needs, preferences and future directions*. Melbourne, Australia: Summer Foundation Ltd; 2007
- ⁹ Australia Government Productivity Commission. *Review of Government Services: Volume F Community Services*. Canberra, Australia 2015.
- ¹⁰ Summer Foundation in conjunction with Monash University Occupational Therapy Department. *Australia's National Disability Insurance Scheme for Young People in Residential Aged Care – Findings from Year One of an Information and Connections Project*. September 2015.
- ¹¹ Winkler, D. F., Farnworth, L. J., Sloan, S. M., & Brown, T. (2011). Young people in aged care: progress of the current national program. *Australian Health Review*, 35(3), 320-326; 2011
- ¹² Winkler D, Sloan S, Callaway L. *Younger people in residential aged care: Support needs, preferences and future directions*. Melbourne, Australia: Summer Foundation Ltd; 2007
- ¹³ Winkler, D., Holgate, N., Sloan, S. & Callaway, L. *Evaluation of quality of life outcomes of the Younger People in Residential Aged Care Initiative in Victoria*. Melbourne: Summer Foundation Ltd. Page 59-66; 2012
- ¹⁴ Summer Foundation in conjunction with Monash University Occupational Therapy Department. *Australia's National Disability Insurance Scheme for Young People in Residential Aged Care – Findings from Year One of an Information and Connections Project*. September 2015.
- ¹⁵ AIHW. Unpublished Data 2015.



SUMMER
FOUNDATION