



National Disability Agreement Productivity Commission Review

Submission by the Summer Foundation, August 2018

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SUMMARY

The Summer Foundation works with governments and stakeholders to stop the forced admission of young people to residential aged care (RAC) – a setting where they experience high rates of marginalisation and isolation. The NDIS has the potential to provide the level of supports necessary for people with complex needs to live independently, avoid admission to RAC and leave it to live in the community.

This submission responds to the Review Terms of Reference:

- Progress against the performance framework of the NDA and the extent to which it has supported outcomes for young people at risk of, or in residential aged care
- Whether the NDA needs updating in light of these considerations, to reflect the changing policy landscape in regard to the needs of YPIRAC

The Summer Foundation endorses the importance of the NDA to represent a commitment of national and state/territory governments to provide funding, policies and programs to prevent young people from being forced into aged care.

The current performance indicator relating to YPIRAC is essential, should be maintained and expanded on to include additional relevant indicators. This will enable a more accurate picture of progress towards providing the necessary housing and supports to enable a good life in the community and significantly reduce the number of YPIRAC.

We recommend the NDA:

1. Continues to include the specific NDA performance indicator: “Percentage of younger people entering, living in, and exiting permanent residential aged care.”
2. Adopts additional performance indicators to cover mainstream health and housing measures in addition to specialist disability services.
3. Introduces benchmarks, targets and measures (such as those in Table 1) in its performance framework that address progress in preventing young people from being forced into aged care.
4. Improves 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 increases its coverage of new benchmark indicators.

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, RAC facilities.

Our vision is that young people with disability and complex support needs will have access to services and housing that supports their health and wellbeing and a good life in the community.

We are committed to working with key stakeholders to achieve accessible and affordable housing for young people with disability with complex support needs. We are committed to working to ensure that the NDIS realises its potential to end the forced admission of young people with disability into residential aged care.

Young people in aged care in Australia

As at June 30 2017, there were 6242 young people in RAC.¹ According to Senate Estimates, over 2000 have now entered the NDIS with the most entering in the past 12 months.²

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.³ 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 community⁴.

The NDIS has the potential to stop young people being forced into RAC. However, they are facing significant barriers to accessing the NDIS. Many do not know how to go about applying for support from the NDIS. They face challenges developing and implementing their NDIS plans. 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.

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 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.

¹ 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>.

² Ibid.

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.

Young people with disability are too often forced to remain in hospital or rehabilitation settings because there is no clear pathway home. 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 can sometimes also lack the necessary expertise or resourcing to support people back into the community in a timely way.

Finally, when living in the community, people with high and complex disabilities 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.

Responses to Questions Outlined in Issues Paper

In light of developments in the disability policy landscape and intergovernmental funding arrangements, is an NDA still required? What should be the state of the NDA?

This review of the National Disability Agreement is timely. With the introduction of the NDIS and the range of other agreements between the Commonwealth and state/territory governments, we need to look at this mechanism and its effectiveness in keeping all levels of government accountable to the needs of young people in residential aged care. For YPIRAC, the NDA has represented a commitment by Commonwealth and state/territory governments to providing appropriate funding, policies and programs to stop young people being forced into RAC.

This commitment continues to be important and relevant today with the introduction of the NDIS and the significant challenges that YPIRAC are having accessing the scheme and securing and implementing their plans. The number of YPIRAC has remained above 6000 since the NDA commenced in 2009. Much more needs to be done so we can resolve the problem. Specifically, there are a range of systems changes that need to occur. We have identified these in Table 1 of our submission and suggested measures or benchmarks that we would like to see included in a future NDA.

As per Table 1, it is our view that the NDA should have a wider scope and cover mainstream services in addition to specialist disability services. The inclusion of performance indicators related to health and housing is critical.

Table 1: Benchmark Targets and Measures for solving YPIRAC by 2021

	Benchmark Target	Measure
1.	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, wellbeing and participation	The total number of young people entering aged care across Australia has decreased by 20%
2.	Reduction in number of young people discharged from hospital into RAC	The number of young people being discharged from hospital to RAC reduces by 20% across Australia
3.	The NDIS has reached all young people in RAC	90% of people under 65 in RAC are connected to the NDIS
4.	Young people with no option other than entering RAC have an NDIS plan in place prior to entry	90% of young people facing admission to RAC have NDIS eligibility established, and have a high quality plan
5.	An increasing number of young people in RAC leave within their first 12 months	Threefold increase in YPIRAC returning to their homes/families
6.	An increasing number of young people in RAC leave within their first 12 months	Threefold increase in YPIRAC returning to their homes/families
7.	The SDA market is developing and creating high quality housing for young people at risk of aged care	1,000 NDIS Specialist Disability Accommodation properties for 1-3 residents have been built or committed

To what extent has the performance framework of the NDA supported improved outcomes for people with disability, their families and carers?

Has it influenced government policy?

We strongly support the continued inclusion of the specific NDA performance indicator: "Percentage of younger people entering, living in, and exiting permanent residential aged care."

Younger people with disability primarily enter RAC because of catastrophic injury resulting in lifetime impairments, or because of deteriorating health exacerbating existing disability, and/or cessation of existing informal care arrangements. Typically their pathway encompasses intensive health sector involvement such as hospital admission over extended periods. During this time they may be accessing the NDIS for the first time, or if existing participants, require an extensive plan review.

For young people who are existing residents of RAC, exercising informed choice to leave residential aged care and live an independent life in accommodation that meets their complex needs, is also dependent on their timely access to NDIS supports through an approved plan.

We believe that the NDA has supported improvements in related policies and practices but more work is required and an ongoing commitment to resolving these issues is needed. We believe that the NDA must continue to hold governments to account.

Does public reporting against the indicators serve to ensure that governments are held accountable for their policies and actions relating to disability? If not, why not, and how could this be improved?

Public reporting on progress of young people with complex needs towards gaining NDIS supports, accessing alternative accommodation and having choices to leave RAC is vitally important to measure progress and hold governments to account.

The coverage in ROGS data of: rate of admissions to RAC excluding respite care; number of permanent aged care residents under 65; number of younger people who exit permanent RAC to home or family by indigeneity and age; are all very important measures that must continue to be collected. They serve as key accountability information to keep the government and government agencies, including the NDIA, focused on solving this problem.

Are the criteria for good performance indicators listed in box 2 suitable? If not, what should be added/changed? How do the existing indicators perform against those criteria?

All criteria to assess performance indicators are relevant and suitable to YPIRAC, however, two criteria are not met by the current performance framework:

- *It is available in a timely manner:* Data available in the ROGS can be out of date. For example the current ROGS, released annually, includes data more than a year old as it covers 2016-2017. The NDIS Quarterly reports are more current. The latest NDIS Q4 covers YPIRAC data to 30 June 2018.
- *The indicator is unambiguous and clear in meaning and interpretation:* The performance indicator as stated is not specific enough to indicate that its intent is to measure reductions in admission to RAC and increases in the rate of exit from RAC.

We recommend that the NDA requires:

- Reports within 6 months after the end of the financial year
- The publication of data reports to cover a more comprehensive set of indicators as outlined in this submission

Are there other measures relating to people with disability and/or their carers that should be added as indicators in the NDA?

Are the current benchmarks of the NDA still relevant? What should they be beyond 2018? For example, what magnitude of change should be targeted and over what time period?

How should the significance of changes in indicators be judged? For example, what magnitude of change in the indicators should be targeted?

The NDA performance indicators framework does not include any benchmarks or targets associated with the indicator of percentage of younger people entering, living in, and exiting permanent residential aged care. The Summer Foundation recommends that benchmarks should be included in the NDA to establish clear outcomes, targets and measures.

We have developed 8 (three-year) benchmark targets to measure progress on a number of key outcomes that together represent real changes to choice and control for YPIRAC. Table 1 includes targets and specific measures for tracking YPIRAC at key points in their entry and exit from RAC, as well as tracking the expansion of housing options. As quantitative measures they set the direction and magnitude of change.

We recommend that the benchmark targets and their measures presented in Table 1 should be added as indicators in the NDA reporting framework to highlight progress towards resolving the problem of YPIRAC.

What level of disaggregation should the indicators provide? For example, should they be articulated at the national or jurisdictional level? Should they be disaggregated by type of support, nature of disability (such as those covered by the NDIS and/or those outside the NDIS)?

All measures relating to the YPIRAC performance indicators should be articulated at national and jurisdictional levels as well as disaggregated by nature of disability and type of support. Jurisdictional data is important for people with complex needs given that many mainstream services such as acute and primary health services are provided by states.

They should also be reported on in relation to a range of characteristics such as indigeneity, age, remoteness, etc. as the NDIS impacts on diverse population groups in different ways.