

SUMMER
FOUNDATION

Summer Foundation
2020-21 Pre-budget Submission

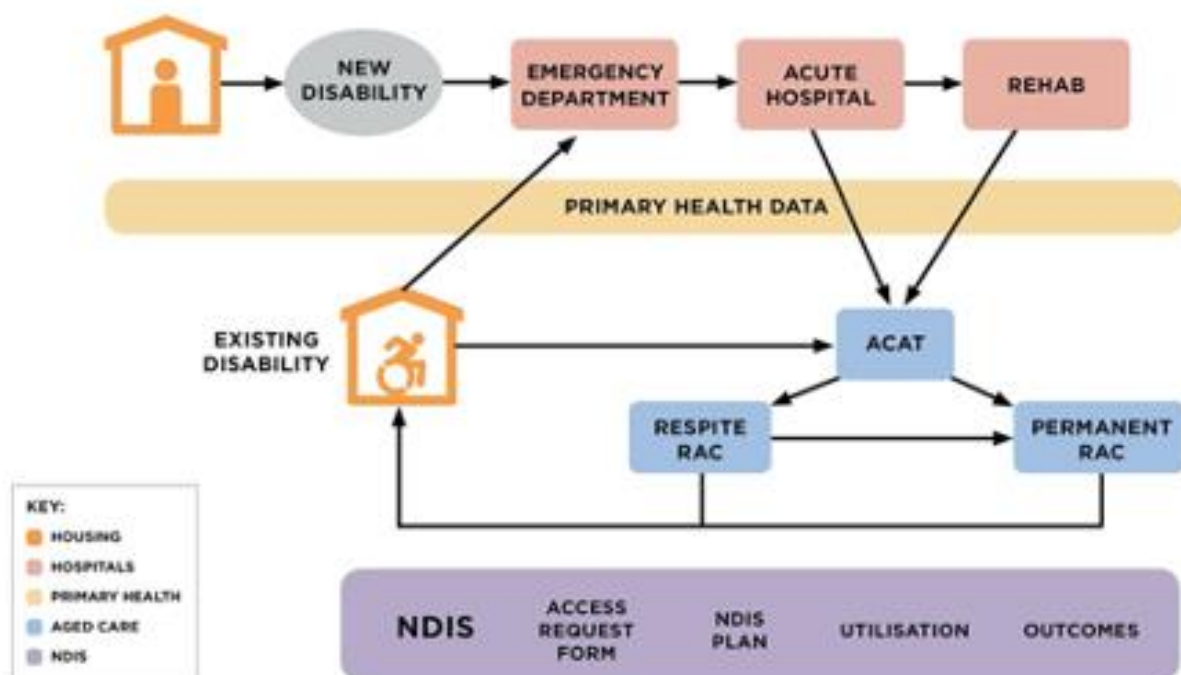
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The issue

Today in Australia more than 5,800 young people with disability live in aged care because there is nowhere else for them. Many are aged in their 30s and 40s, living with people in their 80s. They rarely see family or friends and it is common for young people in Residential Aged Care (YPIRAC) to lose skills and independence. Around half had a partner when they entered aged care and about a quarter are parents of school-aged children. The National Disability Insurance Scheme (NDIS) will help young people with disability to avoid aged care and support them to find more suitable housing. However, the NDIS is only part of the solution. This is a complex problem involving multiple sectors including hospitals, housing, disability, aged care and primary health. Figure 1 depicts the pathways of younger people into residential aged care (RAC) and the sectors involved.

Most young people end up in aged care because they fall through the gap between hospitals and the disability service system. The two systems operate on completely different time frames. For example, if a young person has a very severe brain injury, as soon as they are medically stable and have completed inpatient rehabilitation there is pressure to move them out of a hospital bed. However, the disability sector typically takes months to secure funding for services and determine if a suitable housing and support option is available.

Figure 1: Journey of young people into permanent RAC.



The context

Young people are forced to live in aged care because there is nowhere else for them. The NDIS approach to housing relies on a market-driven model where providers create and maintain housing for people with disability across the country.

The NDIS has an annual recurrent budget of \$700M for Specialist Disability Accommodation (SDA). Over the past two years new SDA dwellings have been built for over 1,200 NDIS participants, with housing for a further 1,800 people currently in the pipeline. There are vacancies in both existing stock and new SDA throughout Australia. Some SDA providers have extended vacancies due to difficulties in connecting with potential tenants. The other limiting factor in the emerging SDA market is the lack of reliable data about the housing preferences and needs of NDIS participants that are eligible for SDA. SDA providers need more detailed information about what to build and where.

The Housing Hub website (www.housinghub.org.au), established in 2017, provides a vital platform for supporting people with disability to find housing. The pilot for the Housing Hub was funded by the Department of Social Services Sector Development Fund. Housing providers are able to list available properties on the website and connect with suitable tenants. More than 2,000 dwellings have been featured on the site and it has had over 144,000 visitors since it was established.

The Housing Hub has evolved and enables housing seekers to explore housing options that meet their needs and preferences; select their housing preferences; where they want to live and with whom, as well as the type of support they want in their home. This data will be used to regularly suggest property matches to housing seekers as well as to encourage housing providers to develop properties where they are needed.

The NDIS, emerging SDA market and The Housing Hub are essential infrastructure for enabling young people with disability to avoid aged care and find more suitable housing. However, YPIRAC have limited social supports and many (48%) have difficulty communicating their everyday needs, which makes navigating the NDIS and the SDA market extremely challenging for them. YPIRAC are not going to be able to make use of the NDIS and the new SDA being built without skilled supports and capacity building.

The solution

Government YPIRAC targets

In November 2019, in response to the interim report by the Royal Commission into Aged Care Quality and Safety, the Australian Government announced new targets, which include:

- no people under the age of 65 entering residential aged care by 2022
- no people under the age of 45 living in residential aged care by 2022
- no people under the age of 65 living in residential aged care by 2025

The Government committed \$4.7 million to:

- establish a Joint Agency Taskforce between the Department of Social Services, Department of Health and National Disability Insurance Agency (NDIA)
- establish a specialist team of 80 complex support needs planners within the NDIA
- work with industry to develop a database of existing and new housing options available now and in the future undertake a detailed analysis of younger people currently living in aged care, as well as up to 2,000 young people at risk of entering aged care, to better inform new policies and pathways to find alternate accommodation

We welcome these targets and the government's commitment to solving this problem.

Summer Foundation is working with the Joint Agency Taskforce and YPIRAC Stakeholder Reference Group to achieve the targets, shape and develop the YPIRAC Strategy, associated actions and implementation plan.

Other essential complementary elements of systems change

We recommend the following budgetary measures to enable the Australian Government to achieve its YPIRAC targets.

These measures include building the capacity of YPIRAC (and their close others) discharge planners, hospitals, support coordinators, allied health professionals and primary health providers. The total cost of these eight measures over three years is **\$15.5M**.

1. Information, resources and peer support for YPIRAC

Most young people who enter aged care come through the hospital system. The decision to enter RAC is often made in the absence of time, knowledge of alternative options or adequate support to make an informed decision. Providing information, resources and peer support for YPIRAC and young people at risk of admission to RAC is critical for both preventing new admissions and supporting YPIRAC to move out. It is vital that YPIRAC have the opportunity to be involved in the co-design of information, resources and services to ensure effective capacity building. YPIRAC and young people at risk also need support to make informed decisions about their housing and support options and to enter their preferences on the Housing Hub. The expansion of the Housing Hub will provide the SDA market with much needed data about the housing needs and preferences of YPIRAC, so that the market can build suitable stock where it is most needed.

There are three crucial elements of capacity building:

- co-design of evidence-based resources with people with disability for YPIRAC to assist them to exercise choice and control regarding housing, support and services
- co-design a peer to peer program to build the capacity of people in YPIRAC and young people at risk of entering RAC

Investment: \$2.6M

2. Capacity building for young people around housing options

The NDIA has stated that 6% of NDIS participants, or 28,000 people will be eligible for SDA. Of this, 14,000 participants have SDA in their plans, however a very small number of this cohort is accessing their funding and therefore utilising SDA to meet their needs, with many in group homes and unaware of the SDA opportunities and potential purchasing power.

Capacity building for young people with disability, and their close others, is needed to understand and explore housing options. The Summer Foundation is establishing the Housing Options Team who will support young people to explore and document their housing needs and preferences. This will enable a targeted search for housing based on housing needs and preferences and empower young people to choose the which best suits their needs.

This will be a national series of workshops in cities and regional centres to:

- disseminate information and resources
- build the capacity of people with disability with complex needs to make an informed choice about housing and support
- support people with disability to enter their needs and preferences on housinghub.org.au

From July 2020 to June 2021 the Housing Options Team will deliver a Roadshow across the country to find and build the capacity of young people. In addition, the team will:

- develop resources to support young people through their housing search
- create a minimum of 1,000 housing seeker profiles to support young people actively search for housing
- establish a phone line to provide SDA advice to young people
- deliver a campaign to showcase Individual Living Options (ILOs)

Capacity building around housing options will also provide the SDA market with much needed data about the housing needs and preferences of YPIRAC, so that the market can build suitable stock where it is most needed.

Investment: \$1.4M

3. Capacity building for hospitals

Given that most young people enter RAC from hospital, improving discharge planning and the health-disability interface is critical to achieving the federal government YPIRAC targets. Over the past two years the Summer Foundation has developed 10 training modules, trained over 5,400 hospital staff and developed a national online Community of Practice (CoP) called [Leaving Hospital Well](#).

To improve discharge planning and prevent admissions of young people to RAC, further investment is required for national face-to-face and online training of discharge planners and expansion of the Leaving Hospital Well community of practice.

The Summer Foundation has also completed needs analyses and provided a bespoke intervention to 30 hospitals to improve discharge planning with NDIS participants. The needs analysis and bespoke intervention process is ready to be systematised and redesigned for rollout on a national scale. The development of self-assessment tools, online resources and templates would increase the efficiency of this process. An initial pilot and evaluation would be conducted to document the costs of the intervention, impact on patient flow and value proposition for hospitals and state and territory health departments. This work has enormous potential to help stop the flow of young people into RAC nation-wide.

Investment: \$2.2M

4. Evidence base for tools and strategies to improve discharge planning

La Trobe University and the Summer Foundation are currently evaluating the discharge process in nine hospitals across Australia to identify facilitators, challenges and barriers to effective discharge. The objectives are to record timeframes of hospital discharge and NDIS processes, measure patient outcomes, and document the lived experience of patients who have been recently discharged from hospital. Phase 1 of the study involves collecting de-identified retrospective and prospective administrative data from nine hospital sites across Australia. Phase 2 involves interviewing discharge planners and one hour semi structured interviews at three approximate time points post discharge (1, 6 and 12 months) with people with disability and a close other. The expansion of this study to four additional major state wide health services in addition to our ongoing analysis of hospital administrative data will provide a vital evidence base for interventions and strategies to prevent new admissions of young people to RAC.

Investment: \$2.1M

5. Specialist housing brokerage service

Training hospital staff and building the capacity of hospitals has improved discharge planning and outcomes for many NDIS participants.

However, a more intensive intervention is required to support the most complex people stuck in hospital and aged care facilities to return to community living. In Victoria alone there are 80 to 90 NDIS participants at any one time stuck in hospital awaiting NDIS decisions, suitable housing, services or home modifications.

The aim of this project is to build the capacity of hospital staff, aged care staff and allied health professionals to support young people with complex needs to explore housing options; to build the capacity of young people with complex needs, and their close others; to explore and consider housing needs, preferences and choice; and to facilitate finding the most suitable long term and interim housing options for young people stuck in hospital beds who are at risk of admission to RAC.

During March – July 2020, as part of Summer Foundation’s COVID-19 response, a specialist housing brokerage service was successfully piloted with hospitals across the country. A secondary consultancy service was provided to enable young people, hospital staff, support coordinators and relevant others to understand housing needs, identify best options through a targeted search; facilitated evidence required to support NDIS planning decisions related to housing and support services; and enabled young people to make an informed choice about housing.

This intensive secondary consultation service will:

- work with staff, NDIA Hospital Liaison Officers, and support coordinators
- work with housing providers (including mainstream, community and SDA) who have vacancies
- identify potential matches
- identify long term and interim housing options that could work with additional health and disability supports and assistive technology
- identify supply gaps in the market and specify the essential elements of any bespoke housing and support options required
- support young people to make an informed choice about housing which suits their needs and preferences

Investment: \$1.2M

5. Transitional housing and support options

Some NDIS participants have long hospital stays while waiting for home modifications, supports or for new housing to become available. Some young people with newly acquired disabilities who are at risk of entering RAC, would benefit from extended rehabilitation and the opportunity to demonstrate their potential for living more independently. The Summer Foundation recently completed an environmental scan of transitional housing and rehabilitation or support services and options for people with disability in Australia.

This report was finalised in February 2020. The next step is to work with each jurisdiction to map the available interim housing options and services relevant to young people at risk of entry to RAC and identify supply gaps.

This information will be used to work with state governments, the NDIA and service providers to develop and implement a strategy that utilises a combination of state funded rehabilitation services, NDIS Medium Term Accommodation Payments and NDIS funded disability supports to expand the range of interim housing and support options available in each jurisdiction.

Investment: \$1.4M

6. Capacity building for support coordinators and allied health professionals

A skilled support coordination and allied health workforce is critical to preventing new admissions to RAC and supporting young people to move out of RAC. The Summer Foundation's [UpSkill program](#) builds the capacity of the support coordinators and allied health workforces to work with YPIRAC and young people at risk of entering RAC.

The Summer Foundation, via the UpSkill program which was launched in September 2018, has delivered more than 67 training sessions to 1,301 participants. A Community of Practice (CoP) has been established for education and information for 'champion' support coordinators and allied health professionals working with younger people residing in, or at risk of entering RAC.

The national expansion of the successful Victorian pilot will enable:

- capacity building of support coordinator and allied health workforces across the country

- a strengthened CoP which facilitates peer to peer learning, real time problem solving and testing of approaches by support coordinators and allied health professionals
- a searchable directory for young people with disability searching for support coordinators and allied health professionals who can provide quality services and have completed the UpSkill training
- the continuous development of relevant training which aligns with changing policy and practice in the NDIS

Investment: \$0.8M

7. Improving primary health for people with disability and complex needs

YPIRAC and young people at risk of entry often have complex health needs that require proactive management to sustain community living. Without adequate primary health care young people moving out of RAC are at risk of hospitalisation and readmission to RAC.

There is enormous potential to leverage mainstream systems (e.g. Practice Accreditation Quality Improvement activities) and existing sources of funding (e.g. Medicare Benefits Scheme payments) to improve primary health services for people with disability. Primary Health Networks (PHNs) are ideally situated to leverage mainstream systems and work with people with disability and complex needs, practice experts and researchers to design, implement, evaluate and refine local solutions. The facilitation of co-design workshops with people with disability is needed to document user experience and explore potential solutions to improving access and quality of primary health services. Potential solutions are likely to include process change, information, resources, tools and training for primary health staff.

Investment: \$2.1M

8. Independent measurement of YPIRAC outcomes

Obtaining the perspective of YPIRAC and young people at risk of entry and measuring outcomes will create a critical feedback loop to inform the YPIRAC Joint Agency Taskforce decisions and track progress towards achieving the 2025 YPIRAC targets. An independent evaluation is needed to follow up and measure outcomes and document the impact of systems change on the lived experience of YPIRAC.

Investment: \$1.7M

About the Summer Foundation

The Summer Foundation, established in 2006, works to change human service policies and practices related to young people (18 to 64 years old) who are living in, or at risk of entering RAC.

Why we exist

The Summer Foundation exists to permanently stop young people with disability from being forced into residential aged care, ensuring people with disability have access to the support required to be in control of where, how and with whom they live.

What is Success

In 5 years we expect the Summer Foundation will have achieved its purpose. With the exception of ongoing entities which originated with the Summer Foundation, there will be no ongoing need for the organisation.

There is significant national scrutiny surrounding the issue of young people in aged care. This scrutiny is driven by the opportunity afforded by the NDIS, the strong recommendations of the Aged Care Royal Commission, and the revised targets in the Federal Government's

Young People in Aged Care Action Plan:

- No people under the age of 65 entering aged care by 2022
- No people under the age of 45 living in aged care by 2022
- No people under the age of 65 living in aged care by 2025

We will regard the issue of young people in aged care as having been resolved when the systems, policy settings and markets consistently enable people with disability to live where, how and with whom they choose, ensuring they experience choice and control equal to people without disability.

Facilitating housing market growth and quality support for people with complex needs and improving the interface between the disability and health sectors is essential if we are to stop young people from being forced into RAC. We are committed to improving policy and practice in all relevant systems such as health, the NDIS, housing and primary and community health to ensure each are able to work together effectively and efficiently to achieve positive outcomes for people with disability.