





The Treasury

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To whom it may concern

Re: <u>Pre-Budget Submission 2020-21 Budget: A blueprint to achieve the Younger People In Residential Aged Care (YPIRAC) targets</u>

The Young People In Nursing Homes National Alliance, Youngcare, Synapse, the Australian Healthcare and Hospitals Association (AHHA) and Aged and Community Services Australia (ACSA), welcome the opportunity to provide this submission in advance of the 2020–21 Australian Government Budget for funding to achieve the YPIRAC targets and meet the needs of the 6000 younger people living in residential aged care and those at risk of placement there.

The Young People In Nursing Homes National Alliance is Australia's first peak body for young Australians living with a disability in aged care facilities (or at risk of placement there), who have high and complex support needs. The Alliance is responsible for the \$244m national Younger People In Residential Aged Care initiative that operated from 2006-11 and was a key instigator of the development of the National Disability Insurance Scheme.

For over 15 years, Youngcare has led the way in providing independence, dignity and choice to young people with high care needs living in residential aged care services. Youngcare develops specialist housing and provides annual grants that enable the younger people they work with to live life to the fullest, regardless of their care needs.

The Australian Healthcare and Hospitals Association is Australia's national peak body for public hospitals and healthcare providers. With a membership that includes state and territory health departments, Local Hospital Networks and hospitals, community health services, Primary Health Networks and primary healthcare providers, aged care providers, universities, individual health professionals and academics, AHHA is uniquely placed to be an independent, national voice for universal high-quality healthcare to benefit the whole community.

Younger Australians living with Acquired Brain Injuries form one of the largest groups of younger people living in residential aged care facilities. As Australia's Brain Injury Organisation, Synapse provides targeted research, and specialist housing, services and support for Australians impacted by brain injury and disability.

Aged and Community Services Australia is the leading national peak body

supporting not for profit church, charitable and for purpose providers of retirement living, community, home and residential care for more than 450,000 older Australians. ACSA works closely with its members, Commonwealth, State and Territory Governments, and their ministerial offices, as well as health, ageing and associated government departments and key advocacy groups. Through its close relationships with stakeholders, ACSA understands the challenges faced by the aged care sector and focuses on providing services and solutions for critical issues.

If you have any further questions regarding this submission, please do not hesitate to contact us.

Yours sincerely

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A blueprint to achieve the Younger People In Residential Aged Care targets

Younger People in Residential Aged Care (YPIRAC)

The tragedy of younger people living in residential aged care (RAC) is a long-standing problem that has seen younger Australians placed in RAC because there were no other options. RAC has been found to be a highly inappropriate place for young people to live as the support available is inadequate to meet their physical, social and emotional needs. These younger people are socially isolated and their experiences have been well canvassed in a number of inquiries and government initiatives.

The 2006-11 COAG Young People In Residential Aged Care Initiative assisted a small number of people under 50 years of age through the provision of disability services, but did not address any of the systemic causes that have seen the incidence of young people being placed in RAC in subsequent years remain largely unchanged.

The change in late 2019 to the Aged Care Assessment process with the introduction of YPIRAC supplementary guidelines for people under 65¹ has slowed the entry of younger people into aged care, but left most of these people in temporary accommodation awaiting permanent housing. Without the development of a sustainable pathway to appropriate housing and support options, this rate of diversion from aged care is not sustainable.

Organisations making this submission

Aged and Community Services Australia (ACSA) Australian Healthcare and Hospitals Association (AHHA) Synapse Youngcare Young People In Nursing Homes National Alliance (YPINHNA)

Our organisations are members of the Younger People In Residential Aged Care Stakeholder Reference Group convened by the Department of Social Services and represent young people in residential aged care and their families, people with acquired brain injury including Aboriginal and Torres Strait Islander people with brain injury, health service providers and aged care providers.

COVID 19

The Covid-19 Pandemic has been devastating for the aged care sector, residents and families, and younger people with disability living in nursing homes who face the same risks and suffer the same anxiety as older residents.

The impact of the pandemic has highlighted the risks faced by younger people not only of living in a large residential institution, but of being subject to (at least) two service systems with different funding, quality standards and service delivery regimes. The inflexibility of these systems in a crisis has been evident, and the lack of

¹ See: https://www.health.gov.au/resources/publications/aged-care-assessment-supplementaryguidelines-for-younger-people

service coordination across the NDIS and aged care has been a significant gap for people negotiating crisis arrangements.

The pandemic has increased the urgency to find alternatives for younger people in RAC and to implement a practical strategy to achieve the targets.

The Royal Commission into Aged Care Quality and Safety (ACRC)

The ACRC inquired into the YPIRAC issue as one of its terms of reference and named action on addressing YPIRAC as one of 3 priorities in its Interim Report: Neglect.²

Hearing evidence that significant gaps exist in the supply of services across multiple programs; and that the cross program service coordination mechanism needed to deliver concurrent services to YPINH doesn't exist, the ACRC identified 'systems wrangling' as an approach that not only enables negotiation, collaboration and cross program service coordination, but is well suited to development of the multi system service responses the YPINH group need, stating that

...[reducing] the likelihood of a younger person's admission into residential aged care...was often enhanced by the role of a dedicated key worker or 'systems wrangler'. These people, often in conjunction with committed family members, work tirelessly to navigate between health, aged care, palliative care and disability systems.³

The ACRC was also clear that "... reducing the number of younger people in residential aged care requires a coordinated, collaborative response..."4 and that unless a dedicated function is developed to deliver that coordinated, collaborative response that "...[focusses] on the drivers of admission to aged care, as well as a firm commitment to ensure that those currently in aged care can leave..."5, there would be no fundamental change to the systems that have given rise to the YPINH problem in the first place.

Unless the YPIRAC Strategy applies a different strategic approach to the ones that, as the ACRC has heard, have consistently failed to resolve this issue and unless dedicated funding is provided to deliver the YPIRAC targets, the government will not achieve the targets it has committed to. In this, we agree with the ACRC's statement in its Interim Report that it

... does not accept that the problem is intractable, only that there has been a lack of will and effort to address the issues that have left younger people to be accommodated in aged care.⁶

⁴ Op. Cit.: 247.

² Royal Commission into Aged Care Quality and Safety; *Interim Report: Neglect, Vol. 1,* Commonwealth of Australia, 2019: 233

³ Op. Cit: 247.

⁵ Ibid.

⁶ Op. Cit.: 252.

If we are to resolve the YPINH issue, once and for all, a strategy must be adopted that uses systems wranglers to facilitate collaboration between service programs and the resolution of identified gaps in the current service systems. The implementation of systems wrangling in the YPIRAC context is more than simply placing a new role into the existing system. It is an approach that changes the way services and government programs relate to each other and work with younger people in RAC.

Australian Government YPIRAC targets

On the 25th November 2019 the Prime Minister announced targets to address the YPIRAC issue. These are:

- 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; and
- No people under the age of 65 living in residential aged care by 2025.

These are ambitious but necessary targets. The ACRC has made the YPIRAC issue a priority and has given guidance about how the solution should be approached. Funding of only \$4.7M was included in the Prime Minister's announcement to address the YPIRAC targets and this has been committed to data collection. However, the Covid-19 restrictions have delayed the collection of any data from individual YPINH or RAC facilities.

The ACRC will certainly have detailed recommendations on YPIRAC in its final report. A 'business as usual' approach cannot achieve the result that younger people and their families expect and the government has committed to by accepting the YPIRAC targets. A dedicated investment in the work to achieve these targets is therefore essential.

The strategy and implementation plan to achieve the YPIRAC targets has been slow to develop and 9 months after the Prime Minister's announcement, a strategy is yet to be agreed or dedicated funding committed.

The ACRC and the YPIRAC Stakeholder Reference Group (SRG) agree that existing systems are inadequate, yet funding for new initiatives to deliver the targets is required. Without these dedicated resources achieving the targets will be extremely difficult.

Implementation imperatives

It is imperative that the Government commit the required resources to the YPIRAC strategy and fast track its implementation. We believe the targets are both achievable and necessary, but relying on current program settings in aged care, NDIS, health services and other jurisdictional programs will not provide a reliable delivery mechanism.

As the Aged Care Royal Commission has indicated, these programs are poorly coordinated with each other and are not targeted to the needs of people in the

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⁷ See: https://www.pm.gov.au/media/response-aged-care-royal-commission-interim-report

YPIRAC cohort. The NDIS mechanism alone is not sufficient to achieve the targets and should not be relied upon for the total solution.

Given the delays in implementing a strategy, a designated program to meet the YPIRAC targets is essential.

Need for a collaborative approach

Young people in residential aged care have concurrent needs for a range of services, such as rehabilitation, mental health, aged care, health care, disability services and housing. Previous attempts to address the YPINH issue have only addressed the single need for disability services, and ignored the integration of concurrent services from other programs.

These previous efforts failed because they were one-dimensional attempts to resolve a multi dimensional problem. It is critical that this 2020 YPIRAC initiative is not set up to fail for the same reasons but delivers a multi-system response that can finally solve this longstanding problem. The involvement of state and territory programs in health, housing, mental health, alcohol and other drugs and justice is central to this collaborative approach. Connections with these programs are best achieved at the local level and in conjunction with existing ministerial and departmental working groups.

Because they have existing relationships with younger residents RAC providers must be key partners in the YPIRAC initiative. Despite being limited by systemic barriers, these providers can provide constructive support to their younger residents' transition if current systemic barriers such as information, access to NDIS funding, and regulatory hurdles are removed.

Engagement with all YPIRAC

Because the engagement with people in the YPIRAC group will commence in the COVID-19 environment with access restrictions at RAC and increased efforts of hospitals to relocate participants, the need for a well coordinated and comprehensive communication mechanism is critical.

As the NDIA continues to extend plan reviews, undertake planning conversations by phone and proactively contact "at-risk" participants, there is a need to ensure that a participant's mainstream interface issues are highlighted and considered at the same time, and services from these mainstream programs secured and implemented alongside any NDIS supports. There is an acknowledged need to increase communication with younger people in RAC to assist in navigating a very complex system. This means that the YPIRAC strategy requires an engagement approach that is not only limited to a single government program – it must have the capacity to bring the disparate programs to bear from across and between levels of government.

For people in the YPIRAC group who are not in the NDIS (estimated to be approximately 1000 people), there is currently no provision in place to engage in the YPIRAC strategy. NDIS personnel cannot undertake this work for non-participants and

given that all YPIRAC are to be covered by the strategy, there needs to be a workforce for this initial stage. The cross-program systems wrangler role is well placed to undertake this work as it can manage people in different service systems.

Workforce development

Ensuring a capable workforce to support YPIRAC through their transition out of RAC into the community is a key part of the YPIRAC strategy. This will involve national recruitment, training and information systems for health, aged care and disability workforces to enable improved collaboration and support for younger residents in RAC and those at risk of entry, who are transitioning to community options.

A YPIRAC specific programmatic response

To deliver the YPIRAC strategy across multiple levels of government, service programs and providers, a strategy-specific structure and workforce is needed. This structure has capacity to negotiate multi-program arrangements for individuals and provide a single point of reference for YPIRAC, their families and service programs.

This structure has 3 components

- A National YPIRAC Coordinating Agency
- A network of community organisations to create local service connections
- A workforce of systems wranglers.

Evaluation

The YPIRAC initiative needs evaluation to ensure ongoing data collection, feedback for government and stakeholders, and as a key reporting mechanism. This will be managed by the National YPIRAC Coordinating Agency and will include an evaluation steering committee made up of the key Australian Government Agencies, participating stakeholders and younger people in RAC. The evaluation will include qualitative and qualitative data collection, and dovetail with existing data activity funded by the Department of Health.

National YPIRAC Coordinating Agency (NYCA)

Because of the complex nature of the YPINH issue and the diversity of government agencies and providers in the YPIRAC arena, a coordinating body is needed that practically connects funding programs, providers and YPINH to the twin aims of the YPIRAC Strategy. The NYCA will deliver this function for the YPIRAC strategy.

As an independent governing body, the NYCA will be comprised of representatives from consumer organisations, NFPs, PHNs, hospital and health networks, residential aged care providers and the NDIS. It engages with key sectors and programs to enable targeted service collaborations, guides development of the new operational pathways needed to achieve the targets and is time limited to 2025 when the YPIRAC initiative concludes.

As a shared governance arrangement engaging with multiple levels of government, the NYCA will lead and coordinate a national response to the YPIRAC targets by

- Working with the jurisdictions, Commonwealth agencies and YPIRAC stakeholders to deliver a policy framework that guides development of the new operational pathways needed to achieve the targets
- Establishing and facilitating cross-sector service networks for the health, disability, mental health, housing, justice and aged care sectors
- Working with First Peoples organisations around specific collaborations and to ensure feedback loops occur in the Strategy
- Providing a single point of reference for all services involved in supporting the YPINH group
- Creating capacity at the community level to divert younger people from aged care placement and support a return to community living for those currently living in aged care facilities
- Fostering collaboration between different service programs around identified YPINH needs
- Supporting a consistent approach to delivery of all YPIRAC service endeavours by facilitating communities of practice with the systems wrangler workforce and service providers
- Coordinating YPIRAC policy development, service development and data collection
- Supporting the PHNs in their management of the wrangler workforce and their strategic engagement with systems and programs providing services to YPINH
- Developing policy and practice material for government and stakeholders
- Managing national data collection and act as a clearinghouse for information on progress towards achieving the targets
- Liaising with the Joint Agency Task Force (JTAF) and the YPIRAC Stakeholder Reference Group (SRG)
- Managing the national evaluation of the YPIRAC Initiative and reporting.

National Network of Community Organisations

A national network of organisations is required to support the wrangler workforce and facilitate local service collaboration and consumer participation.

The Primary Healthcare Networks (PHNs) have the structure and operational maturity to implement the wrangler function; house the wrangler workforce; and activate this workforce to have operational momentum quickly and effectively. The PHNs are nationally linked, funded by the Department of Health (a Joint Agency Taskforce⁸ member) and have existing regional networks that include health and aged care services.

The health sector has been identified as a critical, but underrepresented component of the YPIRAC solution. Locating the wrangler workforce in the PHNs not only establishes an infrastructure of collaborative regional service networks that can provide referral pathways, service development opportunities and greater

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⁸ The Joint Agency Task Force is a multi agency taskforce involving the Departments of Social Services and Health and the NDIS.

engagement with the YPINH cohort. It also creates a structural focus that proactively brings the health sector into play.

Systems Wrangler Workforce

Systems' wrangling is a new human services function designed specifically for the YPINH cohort to facilitate multi system negotiation, collaboration and service coordination for people needing concurrent services from different programs.

The systems wrangler concept was discussed in evidence provided to the ACRC in 2019. It has also been discussed with the YPIRAC Joint Agency Taskforce (JATF) and the Stakeholder Reference Group (SRG) as a instrument that can bring the various service streams the YPINH cohort requires together; and deliver the end to end linking and coordination functions that are central to the YPIRAC Strategy's success.

The SRG has indicated its strong support for the implementation of a systems wrangler model as they recognise its value in bringing the necessary service systems together and enabling joined up service planning and delivery for YPINH. Members of the JATF have also indicated interest in the systems wrangler function as a key strategy to achieve the targets.

Approximately 100 systems wranglers are required to work nationally with younger people living in RAC as well as those who are at risk of entry to residential aged care. Each wrangler will have a rolling caseload of between 15-30 people, will be linked nationally through a community of practice and have access to secondary consultancy from the NYCA.

As a new role specific to the YPIRAC Strategy, the systems wrangler role will complement existing program roles such as hospital social workers, NDIS support coordinators, hospital liaison officers, planners, justice liaison officers, local area coordinators, aged care clinical coordinators and mental health case managers.

Wranglers will support these and other workers to engage in joint service planning, negotiate multi program transition arrangements for the individual, facilitate development of collaborative working relationships and coordinate delivery of these 'joined up' services.

Wranglers will

- Work closely with YPINH and families to establish trusted working partnerships
- Ensure YPINH, their families and representatives are directly involved in decisions
- Work with YPINH who choose to remain in RAC and their RAC provider to improve collaborative work practices by NDIS and RAC providers
- Negotiate multi program inputs to deliver comprehensive transition plans for YPINH
- Develop cross-sector teams to deliver the collaborative design of transition programs for YPINH

- Coordinate implementation of transition plans
- Develop integrated exit/diversion plans that incorporate NDIS and other program supports
- Build the capacity of aged care, mental health, NDIS, housing, justice and health services staff to collaborate with each other and YPINH and families
- Be a primary point of reference for different service programs and YPINH through transition
- Be a primary point of reference for different service programs and YPINH who choose to remain in RAC
- Manage cross program relationships and risks
- Troubleshoot and problem solve
- Collect data, develop case studies and provide reports.

A separate budget submission has been made for delivery of orientation and training for the YPIRAC wrangler workforce.

Budget Requirements

	Year 1 \$	Year 2 \$	Year 3 \$	Year 4 \$	Year 5 \$	Total \$
National YPIRAC Coordinating Agency	\$1.5m	\$1.5m	\$1.5m	\$1.5m	\$1.5m	7.5Mm
Evaluation	\$0.3m	\$0.3,	\$0.3m	\$0.3m	\$0.3m	\$1.5m
System wrangler workforce (inclusive of on costs, administration and management)	\$20m	\$20m	\$20m	\$20m	\$20m	\$100m
Total YPIRAC budget						\$109m

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