Our Care. Our Way:

Transforming care pathways for Aboriginal and Torres Strait Islander Elders

Community-led reforms in response to the
Royal Commission into Aged Care Quality and Safety's Interim Report

April 2020

National Advisory Group on Aboriginal and Torres Strait Islander Aged Care

About NAGATSIAC

This paper has been prepared by the National Advisory Group for Aboriginal and Torres Strait Islander Aged Care (NAGATSIAC).

The NAGATSIAC was ministerially appointed in May 2018, and arose out of the national consultation process to develop the Aboriginal and Torres Strait Islander Action Plans for the Commonwealth's Aged Care Diversity Framework. The Action Plans were the first time effective recognition had been given to the specific needs of Aboriginal and Torres Strait Islander people in the national reform agenda for Australia's aged care system. The working group is funded by the Commonwealth Department of Health.

The NAGATSIAC reaches Aboriginal and Torres Strait Islander communities across all of Australia. The group comprises providers of in-home and residential aged care services, as well as internationally recognised researchers affiliated with multiple research Institutes, cross-disciplinary research projects, and health practitioners across Australia in Aboriginal and Torres Strait Islander aged care.

The role of NAGATSIAC is to:

- promote the views and aspirations of older Aboriginal and Torres Strait Islander people in the development and implementation of Government ageing and aged care policies and strategies;
- provide policy advice to inform Government aged care reforms and associated program design and service delivery to ensure equitable access to aged care, which meets the needs of all older Aboriginal and Torres Strait Islander people; and
- identify priorities and contribute to research to enhance the evidence base on Aboriginal and Torres Strait Islander people's ageing experiences, aged care needs and strategies which are effective in meeting those needs.

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We respectfully acknowledge the First Nations people of Australia and the cultural and spiritual connections

We pay our respect to Elders past and present as well as the existing and emerging leaders who walk together in partnership with this journey

In this document, Indigenous refers to Aboriginal and Torres Strait Islander

Our Care. Our Way

'Elders are our future, our culture'[1]

A powerful testimony at the Aged Care Royal Commission, there has never been a more critical time to understand the significance of this for Indigenous Australians and the care of their Elders.

Elders are wisdom keepers - the custodians of Indigenous tradition and values. As carriers and symbols of knowledge, they impart and sustain a rich cultural heritage from generation to generation, including translating culture into contemporary ways. In this important aspect, the community's future depends on them.

Supporting Elders is essential to the continuation and strengthening of culture for entire communities.

Supporting Elders through maintaining a healthy lifestyle and connection to culture, while helping them to stay independent and at home for longer, therefore goes to the heart of respecting and protecting Elders to undertake this role. This is intrinsic to both their quality of life, as well as essential to the continuation and strengthening of cultures for entire communities.

Sadly, we have let our Elders down and, in the process, diminished the critical role Elders play in sustaining the world's oldest living tradition - including what we all should be learning from them, as those who share this land with our First Australians.

The Aged Care's Royal Commission's Interim Report[2] describes this as a 'shocking tale of neglect', heightened for Indigenous Elders through the multiple additional barriers they face in accessing care. For example, compared to non-Indigenous Australians, Indigenous people are:

- 2.1 times more likely to have a profound/severe core activity limitation[3]
- 3 to 5 times more likely to have dementia[4]
- 2.7 times more likely to live in disadvantaged areas[5]

Overshadowing this data is the sobering and continuing disparity in life expectancy. Our Indigenous Elders are living 8.6 and 7.8 years less than their non-Indigenous male and female counterparts[6]. This, at a time when wisdom and knowledge transfer is most precious. We can do nothing more important than to better nurture this time, to better protect our Elders, to give them more life to give back.

Existing government policies and programs have, however, failed to deliver. This includes both Closing the Gap and aged care specific reforms over the last decade. Even recent additions to the 'policy drawer' such as the Aboriginal and Torres Strait Islander Diversity Action Plan have yet to deliver.

To make any headway past these failures, we now need to 'go back to go forward'. We need to learn from our Elders to recreate care pathways which evoke and draw richly from their antecedent cultural heritage of traditional ways of knowing, doing and belonging. This will give real substance to our oft-spoken respect for Elders 'past, present and emerging'.

Fundamentally, this means that, from now on, these care pathways must be Indigenous-led, designed and delivered.

This requires a transformational shift in the way government and community relate. What the community needs is not further government developed policies and programs, not further ways to navigate a flawed aged care system. Rather, a new paradigm is required, where responsibility, agency and autonomy by Indigenous people themselves create the catalyst for new care pathways. The 'empowered community' is the senior partner and government is a key enabler, facilitator and funder in this Indigenous-led process, not the primary fixer of the problem.

From now on, care pathways for Indigenous Elders must be Indigenous-led, designed and delivered

The Prime Minister himself acknowledged this in his recent Closing the Gap Statement to Parliament[7]. Acknowledging that current paths haven't worked, he described existing policies as a "tale of, good intentions, frustration and disappointment', of 'two and a quarter centuries of Indigenous disempowerment' which have 'robbed Indigenous people of their right to take responsibility for themselves, to make their own decisions and to direct their own futures'. The Prime Minister called for a radical new approach where the gap we wish to close must be accompanied by a willingness to push decisions down to the people who are closest to them: 'We know that when Indigenous people have a say in the design of programs, policies and services, the outcomes are better - and lives are changed'.

This paper is about how to make that commitment real, through seeking the wisdom of, and giving legitimate voice and choice to, our Elders. Critically, it places community in the driver's seat and is community-led every step of the way.

Aligning with key priorities identified in the Aged Care Royal Commission's Interim Report (text box), it sets out a transformational blueprint for three targeted and priority care pathways:

1. Pathways to **access and assessment**
2. Pathways to **home care**
3. Pathways to **hostel care**

It embraces good practices where these already exist but seeks to ensure they are broadened to become usual practice in the way Australia supports its Indigenous Elders.

This is not another policy framework. Rather, it is an immediate 'call to action' for government to give Indigenous people control of the decisions that affect the lives of their Elders – to invest in, and transfer decision-making power to, community controlled organisations to take the lead and pilot these care pathways. It is about improved outcomes that can be achieved by Indigenous people through self-determination, sustaining their cultures and maintaining connections to community.

It is about **Our Care. Our Way.**

Royal Commission Interim Report Conclusions for Indigenous Elders[8]:

The evidence and submissions received to date show that aged care for Aboriginal and Torres Strait Islander people needs to be delivered in ways that are flexible, adaptable a culturally safe. Key features include:

- providing accessible aged care assessment pathways
- integrating aged care with other services, such as primary health, mental health and disability services, including services provided by Aboriginal Community Controlled Health Organisations and other existing Aboriginal health and community organisations
- devising culturally appropriate assessment processes to access aged care
- facilitating aged care provision on Country and 'return to Country' where that is not possible
- greater provision of Aboriginal and Torres Strait Islander-specific services in cities and regional areas
- providing easier access to respite care.

This will ensure that the next steps are ones of action and learning, followed by progressive scalability into sustained and systemic reform of Indigenous aged care across Australia.

Cultural Care Principles

These care pathways are not framed as 'programs' or 'services' but ways for community to honor and support their Elders – calibrated from Aboriginal and Torres Strait Islander terms of reference and drawing strength from rich cultural principles and traditions. These must underpin and transform the way forward.

Cultural Care Principles for Indigenous Elders[9]

a) Care of Elders is a holistic concept:
Indigenous health and wellbeing must be viewed in a holistic context that encompasses mental, physical, cultural and spiritual health. Land is also central to wellbeing. Crucially, it must be understood that while the harmony of these interrelations is disrupted, attempts to promote 'independence, wellness, reablement and restorative care' will fail

b) Elders' right to self-determination:
For Indigenous populations, the evidence shows that the single biggest factor in improving health and social outcomes is self-determination. Self-determination is central to the provision of care to Indigenous Elders and, consistent with Australia's international obligations, a fundamental human right. This includes the design and provision of care by Indigenous peoples themselves. Community Controlled Aged Care and Health Organisations are best practice examples of this self-determination in action

c) The centrality of culture for Indigenous Elders:
For Indigenous Elders, cultural identity is the foundation of who they are. Culture is a key protective factor for health and wellbeing, and cultural expression is healing and has health benefits. Culture must be nurtured to facilitate its expression and continuity for future generations and culturally valid understanding must shape the access, assessment and care of all Indigenous Elders' needs

d) The impact of history in trauma and loss for Elders:
It must be recognised that the experiences of trauma and loss - a direct result of colonialism - are an outcome of the disruption to cultural wellbeing. Trauma and loss of this magnitude, including for Stolen Generation Elders, continue to have intergenerational impacts on Elders and how they view government and access its institutions

e) The impact of racism and stigma for Elders:
Racism, stigma, environmental adversity and social disadvantage constitute ongoing stressors and have negative impacts on Indigenous Elders' health, wellbeing and independence

f) Recognition of the centrality of kinship for Elders:
The centrality of Indigenous family and kinship must be recognised as well as the broader concepts of family and the bonds of reciprocal affection, responsibility and sharing. Elders' Indigenous identity is underpinned by their connection to family and community

g) Recognition of cultural and regional diversity of Elders:
There is no single Indigenous culture or group, but numerous groupings, languages, kinship systems and tribes. Furthermore, Indigenous people live in a range of urban, rural or remote settings where expressions of culture and identity may differ. This includes being responsive to demographic changes such as the rapid population growth of Indigenous Elders in major cities and urban locations, where 79% of Australia's Indigenous population now live

New Pathways at a glance

1 Pathways to Access and Assessment

Participation Rates

- Targets for Indigenous Elder access should be set with appropriate accountability mechanisms, including oversight by COAG's Joint Council on Closing the Gap. An equitable Indigenous participation rate of 7% of home care places is proposed
- Quarantined places for Indigenous Elders should be allocated to support these targets, including to community controlled organisations as preferred providers, and at a regional level to ensure a more equitable distribution in response to the rapid Indigenous population growth in urban areas and major cities

Navigation and Assessment Pathways

- Three community controlled pilots (urban, regional and remote) are proposed which will transform the way Elders are assessed and access care in a culturally safe way
- In these pilots, community controlled providers will:
    - Engage Indigenous 'trusted intermediaries' to provide face to face information and support to assist Elders to navigate through the aged care entry processes
    - Replace existing assessment processes through establishment of regional Indigenous Assessment Teams

2 Pathways to Home Care

- Four community controlled pilots (2 x urban, 1 x regional and 1 x remote) are proposed which will transform the way home care is provided to Elders
- These pilots will leverage and extend the delivery platform of existing Aboriginal Community Controlled Health Service providers to:
    - Expand, or establish for the first time, home-based aged care services to support integrated and seamless health and aged care pathways
    - Privilege and give precedence to cultural determinants in the redesign of care architecture
    - Explore new and creative funding and service models to sustain viable community controlled business operations, optimise synergistic health and aged care outcomes and ensure a harmonious continuum from entry to high-level home care. Characterised by flexibility, these models will not be constrained by existing home care program design, and importantly, must include expanded reach of the National Aboriginal and Torres Strait Islander Flexible Aged Care Program (NATSIFACP) into urban and home care settings

New Pathways at a glance

3 Pathways to Hostel Care

- Three urban pilots are proposed, including in major city locations, to trial new culturally responsive residential solutions for Elders
- To be operated by community controlled providers, key design characteristics would include:
  - Provision of care beyond what level 4 Home Care Packages can currently support, including both on a permanent and respite tenured basis in 'hostel' type supported accommodation – typically around 20 home-like places
  - Maintenance of family and community connectivity
  - Operated by or in partnerships with Aboriginal Community Controlled Health Services who can provide the vital wrap around primary and specialist services
  - Block funding to sustain viable business operations and optimal integration of health and aged care outcomes. Similar in approach to the proposed home care pathways, this will include new funding models, including any appropriate blend and expansion of NATSIFACP, Multi-Purpose Service (MPS) funding for urban settings

4 Indigenous Workforce

- A critical success factor in the proposed pilots will be a well-trained Indigenous workforce
- This will require additional support in the form of:
  - Immediate allocation of additional places under the Commonwealth Health Workforce Program's Indigenous Employment Initiative (or similar) to subsidise the employment and training (including accredited) costs for all Indigenous workers required to undertake the above pilots
  - Funding for NAGATSIAC to lead the development of a comprehensive and national Indigenous Aged Care Workforce Plan. This will complement work already agreed by COAG to develop a National Aboriginal and Torres Strait Islander Health and Medical Workforce Plan

Transformed Care Pathways

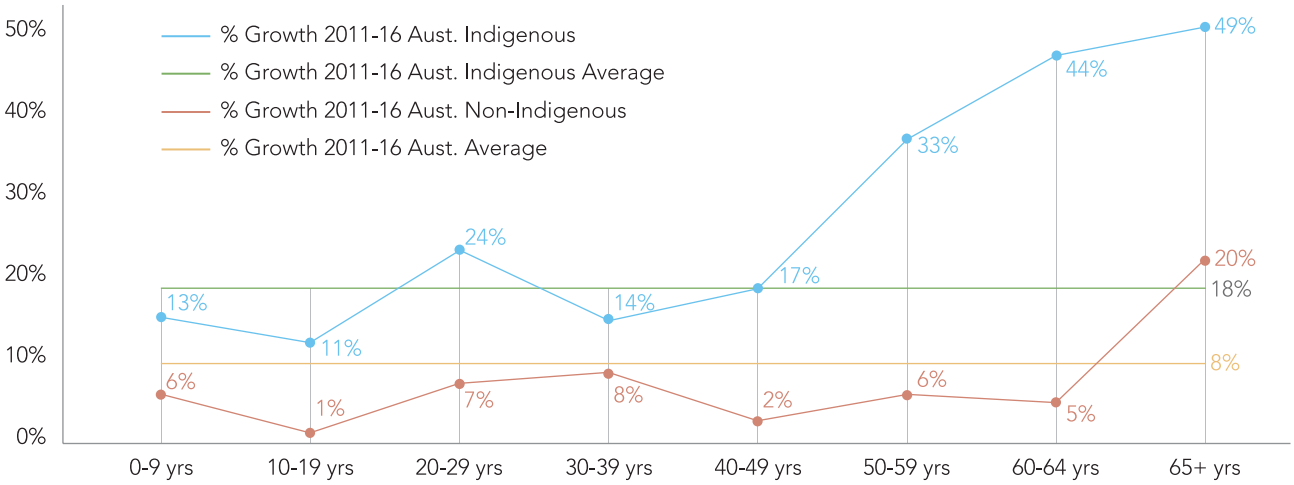
1. Pathways to Access and Assessment

1.1 Participation Rates

What we know

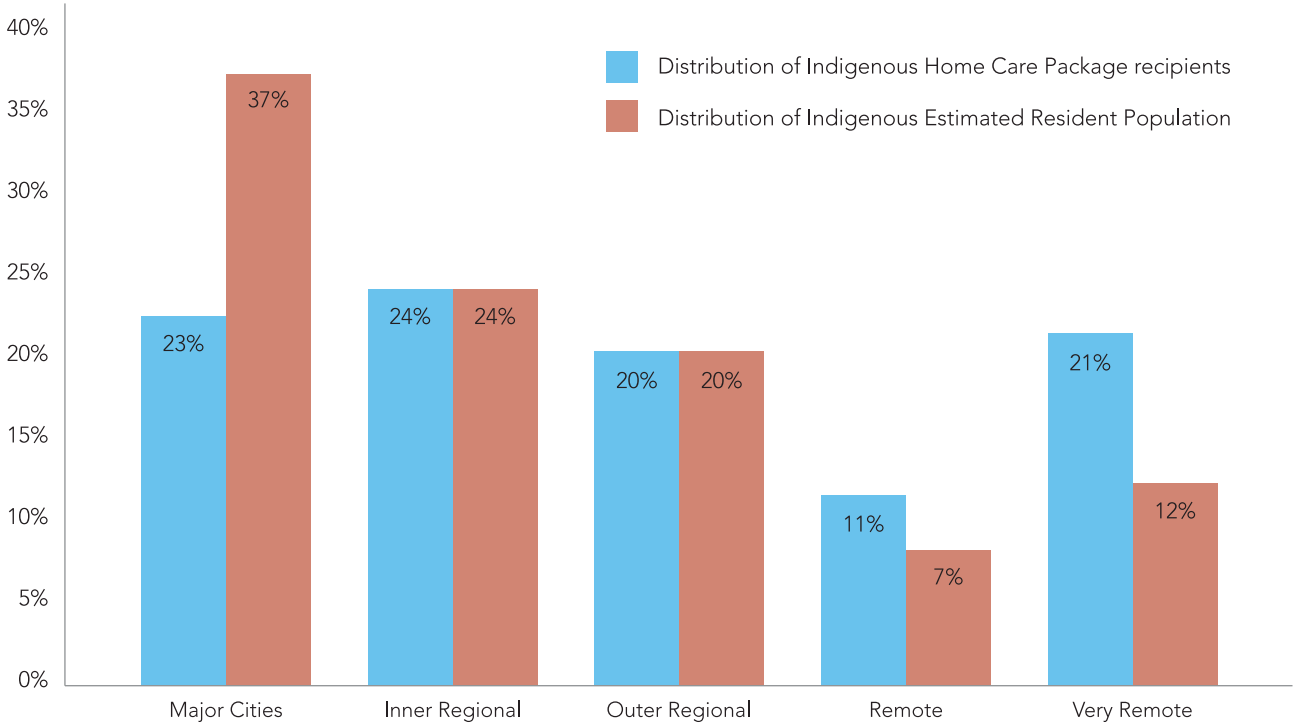
- Despite poorer rates of health and disability, Indigenous Elders are under-represented in the aged-care system. Compared to their 3.4% representation of the population, Indigenous Elders constitute only 1% (at June 2019) and 2.8% (2018-19) of the residential aged care and Commonwealth Home Support Program (CHSP) clients respectively[10]
- There is also a lack of government aged care funding and program agility to match the pace and location of Australia's rapidly growing and ageing Indigenous population. Whilst the total Indigenous population is projected to grow by 59% between 2011 and 2031, the Indigenous population aged 65 and over is projected to grow by 200%[11]. Figure 1 shows the Indigenous Elders intercensal growth (2011 to 2016) as the fastest-growing Indigenous age cohort – significantly higher than the non-Indigenous aged growth rate.

Figure 1: Intercensal growth rates (2011 -2016) by Indigenous status and age, National
Source: ABS Census data (2016)



- This increase is coupled with the rapid urbanisation of the Indigenous population, which represents one of the most striking demographic trends since Indigenous populations were first counted. For example, 79% of Indigenous people now live in urban areas[12], with the largest cohort (37%) of Indigenous people living in Major Cities[13], yet funding and access are not commensurate with this changing need. The fastest-growing Indigenous populations are in these major urban cities, with population decline or slowed growth in remote and very remote regions. As an example, Figure 2 highlights the significant access gap of Indigenous Elders receiving Home Care Packages (HCP) in Major Cities compared to remote and very remote areas.

Figure 2: Indigenous Home Care Package (HCP) recipients by Remote Category, National, 2015-16
Source: ANAO Aged Care Audit (2017) and ABS Census data (2016)



A New Pathway

- Targets for Indigenous Elder access should be set with appropriate accountability mechanisms, including oversight by COAG's Joint Council on Closing the Gap. An equitable Indigenous participation rate of 7% of Commonwealth Home Support Program (CHSP) and Home Care Package (HCP) recipients is proposed, based on their share of the population, their elevated levels of health and disability needs and a cultural preference for home-based rather than residential care options
- Quarantined places for Indigenous Elders should also be allocated to support these targets, including to community controlled organisations as preferred providers, and at a regional level to ensure a more equitable distribution in response to the rapid Indigenous population growth in urban areas and major cities.

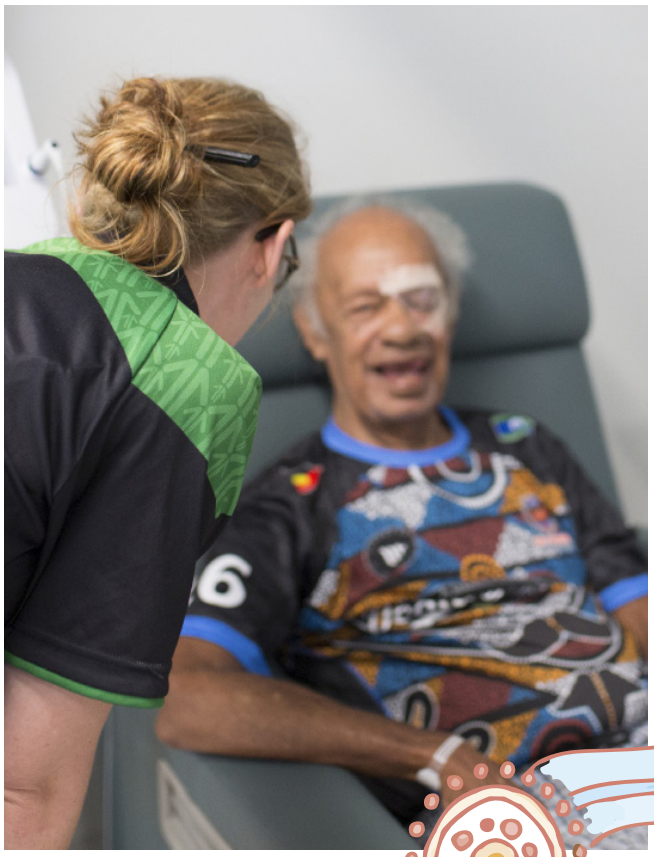
1.2 Navigation and Assessment Pathways

What we know

- Navigating the aged care system, including through the impersonal and highly bureaucratic My Aged Care entry portal, is a major barrier for Indigenous Elders. Further, a focus on the individual can adversely impact on family involvement in assessment and care decisions
- Compared to their 3.4% representation of the population, Indigenous Elders are only receiving half their share of (1.9%) of ACAT assessments[14]
- Elders' care is compromised due to the lack of cultural acuity of assessors and resultant improper assessment of needs. For example, Indigenous Elders are under-represented in higher-level HCPs despite their more significant health and disability issues
- There is no performance metrics to ensure accountability for the cultural credentials of assessors or the cultural quality of assessments undertaken for Indigenous Elders
- Indigenous Elders favour assessment and service provision from community controlled organisations

A New Pathway

- The recurring evidence is that Indigenous people will access services and actively engage in, and benefit from, health-improving, independence promoting and capacity building behaviours when they are culturally connected to community controlled providers and can develop trusting relationships with Indigenous health and aged care assessors and workers
- Three community controlled pilots (urban, regional and remote) are proposed to model this approach
- In these pilots, community controlled providers will:
    - Engage Indigenous 'trusted intermediaries' to provide face to face information and support to assist Elders to navigate through the aged care entry processes
    - Replace existing assessment processes through establishment of regional Indigenous Assessment Teams. This will include a combination of leveraging existing Aboriginal Community Controlled Health Service Care Coordinators to undertake low-need assessments and recruitment of appropriately skilled Indigenous Assessors for high-need assessments. Relevant competencies and standards will be in place.



2. Pathways to Home Care

What we know

- Major contributors to the underrepresentation of Indigenous Elders accessing quality home care are the barriers they face accessing mainstream service providers. These include the lack of cultural capability in service provision and racism which continues to manifest in society
- The importance and role of family and community as part of the cultural care construct of Indigenous Elders is also often at odds with the current aged care reform focus on the individual and 'consumer directed care'
- There is a lack of community controlled providers delivering aged care services. This 'thin' market strongly mitigates against chances that the current model can deliver culturally safe outcomes, including a best practice approach to integrated and holistic health and aged care
- Coupled with the above, a broader trend away from block funding presents significant impediments to optimal viability and flexibility for community controlled aged care providers. The Indigenous targeted and more flexible aged care programs that do exist - for example, National Aboriginal and Torres Strait Islander Flexible Aged Care Program (NATSIFACP) and Multi-Purpose Services (MPS) - are primarily restricted to selected remote and rural areas and are not supporting the bulk of Indigenous Elders, who now live in major cities and urban regions.
- By contrast, the health care needs of Indigenous Australians are currently better served by the 144 Aboriginal Controlled Community Health Services operating across remote, regional and urban settings. These health services have unique cultural competency, but in many cases not yet the opportunity or capacity, to navigate Indigenous Elders through the fractured Australian aged care system. Given adequate capacity-building support, they are, however, considered future agents of choice to expand into aged care assessment and service delivery.

2. Pathways to Homecare

A New Care Pathway

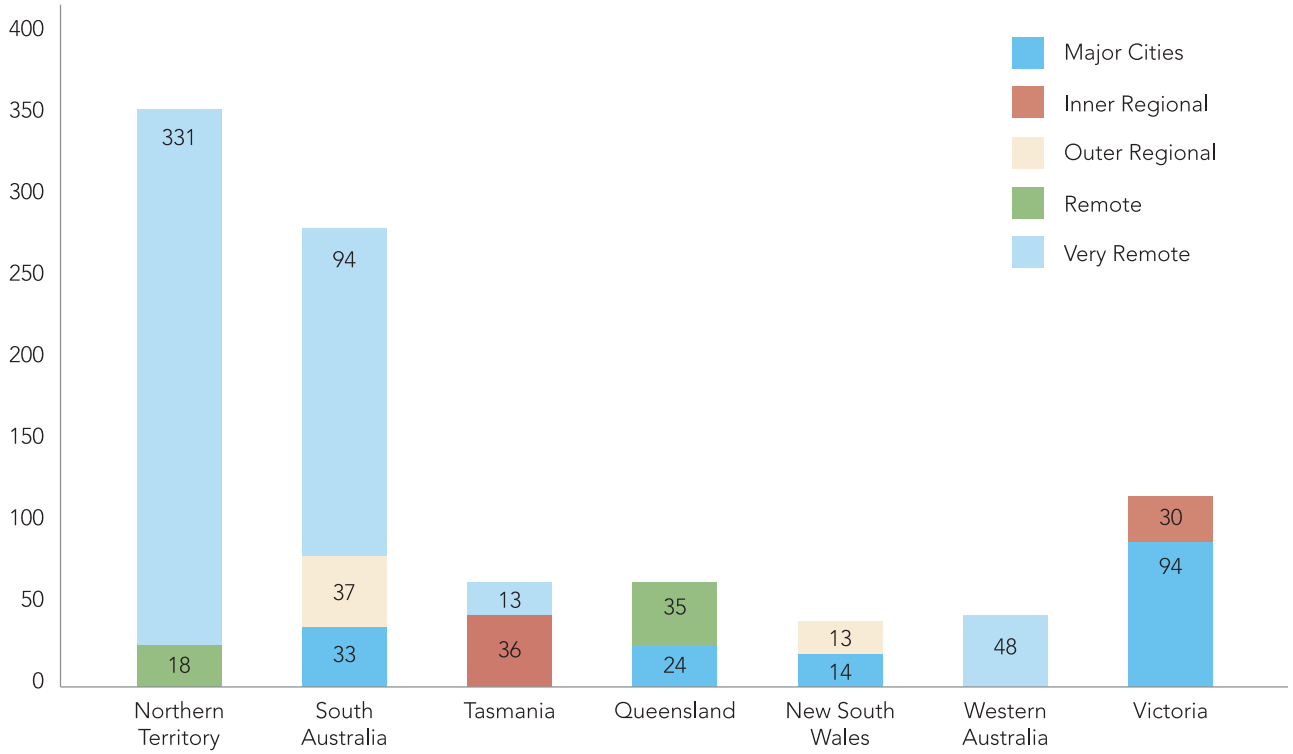
- Best practice care models for Indigenous Elders support a holistic, coherent and navigated service journey for the client. Operating from the premise of a 'one-stop-shop' for all clients, in these models, there is no wrong door to access a full range of wrap-around health, family, mental health, aged care and disability services. This ensures optimal benefit and the most relevant care pathway for each client
- Also fundamentally important, and one exemplified by community controlled providers is that best practice care planning and delivery for Indigenous Elders is designed and operates from an Indigenous worldview. Central to this is the cyclical and reciprocal relationship between culture and wellbeing, whereby nurturing culture keeps communities and their future generations, healthy and strong[15]. These 'cultural determinants' are therefore critical to closing the gap for Indigenous Elders and should be respected, understood and embraced in all aspects of program design and delivery. For example, cultural identity, connection to family/community/land and cultural healing are critical success factors in supporting goal attainment and increased independence. Similarly, the modality of service delivery is framed around how 'mob' engages with each other and their support workers – which often is reflected in collectivism, ways of belonging and family-centric, rather than an individualistic focus
- Four community controlled pilots (2 x urban, 1 x regional and 1 x remote) are proposed to model this best practice
- These pilots will leverage and extend the delivery platform of existing Aboriginal Community Controlled Health Service providers to:
    - Expand, or establish for the first time, home-based aged care services to support integrated and seamless health and aged care pathways
    - Privilege and give precedence to cultural determinants in the redesign of care architecture
    - Explore new and creative funding and service models to sustain viable community controlled business operations, optimise synergistic health and aged care outcomes and ensure a harmonious continuum from entry to high-level home care. Characterised by flexibility, these models will not be constrained by existing CHSP and HCP program architecture, and importantly, must include expanded reach of the NATSIFACP, or an adapted model, into urban and homecare settings.

3. Pathways to Hostel Care

What we know

- Even without taking into account their higher rates of illness, disability and dementia, Indigenous Elders are seriously under-represented in residential facilities. Compared to their 3.4% representation of the population, Indigenous Elders make up only 1% of residents and uptake of dementia services is very poor
- With very few community controlled residential providers, 78% of the few Indigenous Elders accessing residential care do so from mainstream services[16]. The living environments of these mainstream facilities have no appeal to Indigenous Elders. They are a last place of choice due to previous experiences with institutional care, and an inherent cultural disconnect from family and community, with these institutions appearing unwilling to undertake the adjustments necessary to make their facilities culturally appropriate. All three peak aged care bodies made this very clear in their lack of support for the first, and ministerially commissioned, *Aboriginal and Torres Strait Islander Action Plan*[17]
- The viability thresholds (minimum of 60 places) dictated by the Aged Care Funding Instrument (ACFI) funding model present challenges for expansion of community controlled residential facilities
- In preference, models such as the NATSIFACP promote culturally safe care through smaller-scale operations which maintain a proximate connection with family and community and are underpinned by more sustainable block funding arrangements. The availability of these NATSIFACP places is, however, severely limited both in number and distribution. For example, of the 820 existing places nationally, only 10% are in Queensland and NSW (which have 60% of Australia's Indigenous population), and only 20% are in Major Cities, despite these being the largest and fastest-growing Indigenous population region (37% of Australia's Indigenous population). Figure 3 refers.

Figure 3: Allocation of NATSFACP places by Jurisdiction and remoteness category, 2015-16
Source: ANAO Report No. 53, 2017, Indigenous Aged Care



3. Pathways to Hostel Care

A New Care Pathway

- An initial step to this urgent need for culturally responsive residential solutions includes the trial of innovative urban community controlled 'hostel' type supported accommodation, particularly in the rapidly increasing major cities demographic. These community hostels would typically support around 20 'home-like' care places, filling the gap in the current cultural continuum of care for urban Indigenous Elders
- Three urban pilots are proposed to model this approach, including in major city locations. To be operated by community controlled providers, key design characteristics would include:
    - Provision of care beyond what level 4 HCPs can currently support, including both on a permanent and respite tenured basis
    - Maintenance of family and community connectivity
    - Operated by or in partnerships with Aboriginal Community Controlled Health Services who can provide the vital wrap around primary and specialist services
    - Block funding to sustain viable business operations and optimal integration of health and aged care outcomes. Similar in approach to the proposed home care pathways, this will include new funding models, including any appropriate blend, expansion or adaption of NATSIFACP, MPS and HCP funding for urban settings.

Pilot Projects

It is envisaged that NAGATSIAC will work closely with the government to advise and negotiate suitable pilot locations and scope as proposed above. Considerations will include:

- Targeting urban, regional and remote locations to design pilots tailored to the context
- Ensuring pilots are Indigenous-led through the engagement of community controlled providers. This will require additional capacity-building investment, and change management support, where necessary
- Harnessing the capabilities and benefits of scale, through a preference for regional approaches - including, for example, several community controlled providers working as a network rather than individually
- Exploring opportunities for a range of pilot designs and scope, including, for example, comprehensive trials to demonstrate the continuum of care across all pathways (access, assessment, home care and residential)
- Ensuring all pilots align with the cultural care principles outlined in this paper
- Providing capacity for robust evaluation frameworks to build the evidence for planned and subsequent continuation and also replication on a broader scale. All pilots will be for an initial three years and benefit from joint monitoring arrangements as part of a community/government partnership

4. Indigenous Workforce

As already indicated in this paper, Indigenous people are often reluctant to engage with mainstream providers based on past negative experiences including perceived inconsistent, unreliable or culturally insensitive service provision.

A key enabler of culturally safe aged care service delivery is, therefore, a well-trained Indigenous workforce. This has been the overwhelming experience of community controlled providers who are already providing care for their Elders, and who identify this as the key success factor in building trusting relationships with clients.

This will also be a critical success factor in the pilot projects proposed in this blueprint, however accelerated effort and additional support is required to recruit and train a capable Indigenous workforce.

This support should take the form of:

1. Immediate allocation of additional places under the Commonwealth Health Workforce Program's Indigenous Employment Initiative (or similar) to subsidise the employment and training (including accredited) costs for all Indigenous workers required to undertake the proposed pilots
2. Funding for NAGATSIAC to lead the development of both a comprehensive and national Indigenous Aged Care Workforce Plan and work undertaken to implement the Commonwealth's Aged Care Workforce Strategy[18]. This will complement work already agreed by COAG to develop a National Aboriginal and Torres Strait Islander Health and Medical Workforce Plan.

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