

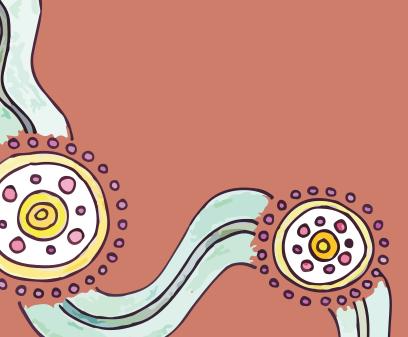
# **Background Paper**

# Our Care. Our Way:

Aboriginal and Torres Strait Islander Aged Care

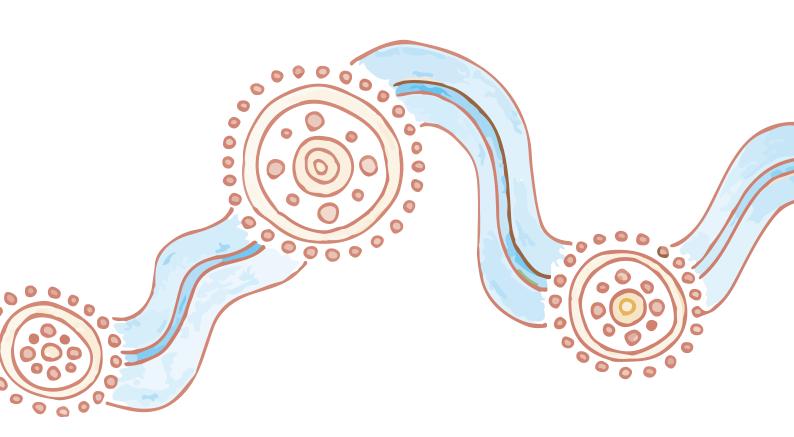
April 2020





# Contents

1. Preface	2
Introduction	2
Executive Summary	3
Acronyms and abbreviations	4
2. Underrepresentation and contributing factors	5
Need and service provision comparison: Aboriginal and non-Indigenous seniors	5
Data model: underrepresentation	7
Access pathways	10
In-home care	12
Residential aged care	17
Funding model	18
3. Likely roadblocks	20
What would a culturally sensitive aged care system would look like?	20
Perceived 'conflict of interest'	20
Indigenous workforce	21
References	22



#### 1. Preface

#### Introduction

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

The NAGATSIAC was established 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 that 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 working 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 purpose of this paper is to articulate the perspective of the NAGATSIAC on how the aged care system redesign, currently underway by the Commonwealth Government, can incorporate mechanisms and policies that would:

- improve Aboriginal and Torres Strait Islander Australians' access to appropriate aged care services
- provide safeguards within the aged care system that protect this group from the common experience of 'falling through the cracks' in terms of service provision meeting levels of need.

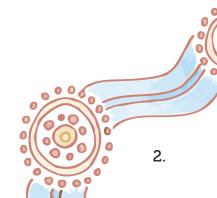
This paper will consider underrepresentation and contributing factors for the following three areas of the aged care system, as well as some likely roadblocks in system redesign:

- access pathways
- in-home packages
- residential aged care

The NAGATSIAC submission to the Royal Commission into Aged Care Quality and Safety (September 2019) can be considered as supplementary reading to this strategy paper, as it offers extensive explanations of Indigenous Australians' problematic experiences of the current aged care system.

This paper was authored by Dr Teagan-Jane Westendorf.





#### **Executive summary**

This paper intends to provide background information and reasoning to support the NAGATSIAC's recommendations for how the upcoming aged care system redesign can best ensure equitable access and service delivery to Indigenous Australians aged 50 years and over. To this end, this paper serves as a supporting document to the accompanying NAGASTIAC paper: 'Our Care. Our Way: Transforming care pathways for Aboriginal and Torres Strait Islander Elders'.

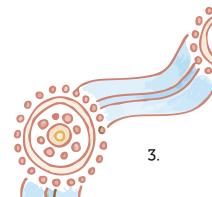
Indigenous Australians eligible for aged care (i.e. people aged 50 years and over) experience significantly higher rates of chronic illness than non-Indigenous Australians eligible for aged care (i.e. people aged 65 years and over). Yet this increased need is not reflected in increased, or even parity of service provision in the current aged care system. The representation of Indigenous Australians in aged care system data evidences that the current system does not enable equitable access and service delivery for non-Indigenous and Indigenous Australians:

- Indigenous Australians experience more inhibiting factors in access pathways.
- They are over-represented in the lower-level Commonwealth Home Support Packages and (CHSP) funding for in-home care.
- They are under-represented in the higher-level Home Care Packages (HCP) funding for in-home and residential aged care.

This paper argues that this lack of parity is contributed to by a range of factors that can all be linked back to the vulnerabilities of the Indigenous cohort (socio-economic, political and health factors), which have resulted from the colonial history of Australia.

To begin addressing the significant gaps in disability, chronic illness and mortality between Indigenous and non- Indigenous senior citizens, the aged care sector redesign must address the lack of parity in aged care service access and provision by these two cohorts. If equity and dignity are to be afforded to Indigenous people eligible for aged care services, the system must be redesigned to accommodate their vulnerabilities and needs at every stage from application and assessment through to service delivery.





#### **Acronyms and abbreviations**

This paper uses 'Indigenous' to refer to 'Aboriginal and Torres Strait Islander' for brevity. It uses 'Indigenous' instead of 'Aboriginal' to avoid excluding 'Torres Strait Islander' for brevity.

**VACCHO** – Victorian Aboriginal Community Controlled Health Organisation

**ACCO** - Aboriginal Community Controlled Organisation

**CHSP** – Commonwealth Home Support Program

**HCP** – Home Care Packages

**NATSIFACP** - National Aboriginal and Torres Strait Islander Flexible Care Program

NAGATSIAC - National Advisory Group for Aboriginal and Torres Strait Islander Aged Care

IUIH - Institute of Urban Indigenous Health

**AAG** - Australian Association of Gerontology

ATSIAGG - Aboriginal and Torres Strait Islander Ageing Advisory Group

PHNs - Primary Health Networks

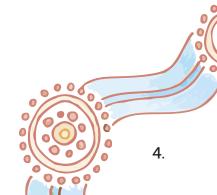
**RAS** – Regional Assessment Service

**ACAS** – Aged Care Assessment Services

MAC - My Aged Care

**NSAF** - National Standardised Assessment Form

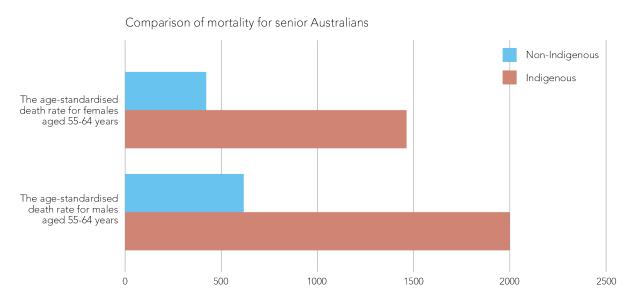




# 2. Underrepresentation and contributing factors

#### Need and service provision comparison: Aboriginal and non-Indigenous seniors

Indigenous Australians eligible for aged care (i.e. people aged 50 years and over) experience significantly higher rates of chronic illness than non-Indigenous Australians eligible for aged care (i.e. people aged 65 years and over). This is evidenced in their higher mortality rates.

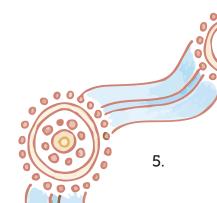


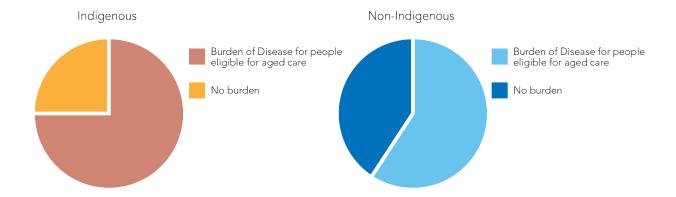
Note: The age-standardised death rate is measured per 100,000 population

Yet this increased need is not reflected in increased, or even parity of service provision in the current aged care system.

The burden of disease (per 1,000 of each cohort) of Indigenous Australians over 50 years old is 749.5, while for non-Indigenous Australians over 65 years old, it is 593.2. This is a significant difference of 156.3 per 1,000 people in each cohort<sup>1</sup>. This does not even account for the significantly lower rate at which the Indigenous cohort engages with healthcare services, which suggests the difference is likely even greater than the available data indicates. This suggests that the need for aged care services among Indigenous Australians over 50 is significantly higher than the need of non-Indigenous Australians, despite the rate of services being accessed and received being significantly lower (see section below titled 'Data model' for further details on this estimation).







Note: Burden of disease is measured per 1,000 of each cohort

The non-Indigenous cohort, even as the better serviced group, still experience significant unmet need and insufficient services in the form of:

- waiting times of 152 days on average for senior Australians to be admitted to residential aged care<sup>2</sup>,
- 69,086 people awaiting their approved level Home Care Package at 30 September 2018, yet to be offered a lower level package<sup>3</sup>,
- 127,000 people on the waiting list for a home-care package, with the average wait time for those needing the highest-level package being 22 months<sup>4</sup>,
- 16,000 people died while waiting for their Home Care Package in the 12 months ending in June 2018<sup>5</sup>.

Due to difficulty gathering data<sup>6</sup>, the level of need of Indigenous Australians over 50 is not known. In contrast, we do have enough data to have a general idea of the level of need of non-Indigenous Australians over 65 years of age: 1,358,245 people needing services<sup>7</sup>. For the non-Indigenous cohort, we also know the extent to which need is currently being met, i.e. that 95% of people are receiving some level of services<sup>8</sup> (though the sufficiency of many service allocations has been called into doubt by the Royal Commission<sup>9</sup>).

We do know Indigenous Australians eligible for aged care experience higher rates of chronic illness<sup>10</sup>, yet apply for, access and receive appropriate levels of aged care at a much lower rate. This suggests that Indigenous Australians are significantly underrepresented in aged care services, given their rate of need as a population (see below section titled 'Data Model'). The current rate of service delivery to this cohort would have to increase by 40.4% to achieve parity of need to service use / delivery between these two cohorts. This calculation assumes that the need of the Indigenous cohort is at least equal to the need of the non-Indigenous cohort (see page 9 for calculation).

To begin addressing the significant gaps<sup>11</sup> in disability, chronic illness and mortality between Indigenous and non- Indigenous senior citizens, the aged care sector redesign must address the lack of parity in aged care service access and provision by these two cohorts. The recommendations



for system redesign that this paper presents are informed by significant empirical research by academics in the field of trauma-informed, culturally sensitive health and human service provision; and by the practical, service-provision experience of Indigenous community-controlled health organisations and aged care service providers.

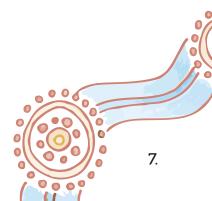
It is urgent that these recommendations are considered by the Commonwealth Government before the system redesign is finalized this year. It is also timely, given the justified concern of the Commonwealth Government with increasing the rate of improvement on Closing the Gap targets in light of the recent Closing the Gap 2019 report, which showed that the only target pertaining to senior citizens (i.e. to close the gap in life expectancy by 2031) is "not on track"<sup>12</sup>.

### **Data model: underrepresentation**

These calculations of need assume that the percentage need (i.e. percentage of total cohort) for some level of aged care services of the Indigenous cohort, is at least the same as the percentage need of the non-Indigenous cohort. This assumption is based on:

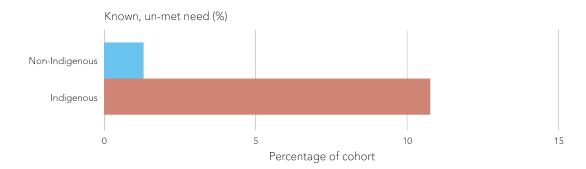
- knowing the number of people in the non-Indigenous cohort who need some level of services, and those who are currently receiving some level of services<sup>13</sup>
- knowing that the majority of the non-indigenous cohort will apply for services if and when they need them, except minority sub-groups such as homeless people over 65 years of age who lack the resources and support networks to access and navigate the system<sup>14</sup>
- knowing Indigenous Australians eligible for aged care experience higher rates of illness and disability (e.g. 3 to 5 times the rate of dementia<sup>15</sup>), yet engage with the aged care and health care systems at a much lower rate<sup>16</sup>
- knowing the number of people in the Indigenous cohort who are currently receiving some level of services<sup>17</sup>
- not knowing the number of people in the Indigenous cohort who need some level of services



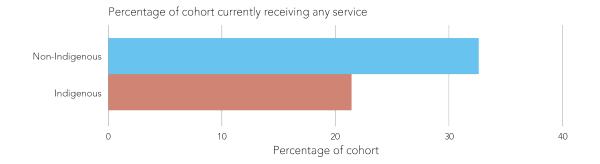


The differences between need and service delivery for non-Indigenous Australians over 65 years old, and Indigenous Australians over 50 years old, are significant:

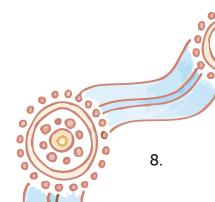
- difference in need: We do not know the true need of the Indigenous cohort, but assume it is at least the same as the known need of the non-Indigenous cohort: 34.5%
- difference in un-met need:
  The known, un-met need of the non-Indigenous cohort is 1.8% (69,086 people).
  The known, un-met need of the Indigenous cohort is at least 11.2% (13,700 people).



difference in service use / delivery:
 23.3% of the Indigenous cohort currently receive some level of aged care services (28,614 people).
 32.8% of the non-Indigenous cohort currently receive some level of aged care services (1,289,159 people).







To achieve parity of need to service delivery between these two cohorts (i.e. that service delivery meets need to the same degree it does for the non-Indigenous cohort) services delivered to the Indigenous cohort must be increased according to the following calculations:

- The use / delivery of services to the Indigenous cohort is currently 9.42% lower than that of the non-Indigenous cohort (i.e. 32.76% 23.34% = 9.4%).
- The known, un-met need of the Indigenous cohort is 9.4% higher than the known, un-met need of the non-Indigenous cohort,
- If the use / delivery of services to the Indigenous cohort was the same (i.e. same percentage of the whole cohort) as it currently is for the non-Indigenous cohort (i.e. 32.8% of the whole cohort), it would be 40,164 people. That is 11,550 additional people than are currently serviced in the Indigenous cohort, or an increase of 40.4% on the current rate at which this cohort receives services.
- Therefore, services delivered to the Indigenous cohort should be increased by 40.4% to achieve parity of service delivery with the non-Indigenous cohort (i.e. 32.8% receiving services, with a total known need of 34.5% if the total cohort), assuming the former have at least the same rate of need as the latter does.

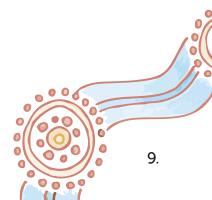
To meet the total known need of these cohorts, i.e. to deliver services to 34.5 % of each cohort:

- service delivery to the non-Indigenous cohort must increase by 1.75%.
- service delivery to the Indigenous cohort must increase by 11.2%.

Given that we do not know the true, total need of aged care services of the Indigenous cohort, this figure is likely significantly higher that 11.2%. This suggests that this cohort would have to be overrepresented in aged care service delivery in order to begin addressing their overrepresentation in disability and chronic disease cohorts.

The significant differences cited above evidence the roadblocks faced by Indigenous Elders in the aged care system, which occur regarding access pathways, in-home care, and residential aged care, and are discussed below.





### **Access pathways**

Eligible Indigenous Australians are assessed at half the rate of eligible non-Indigenous Australians <sup>18</sup>. What impedes access to services for Indigenous Australians over 50 years of age?

Indigenous Australians commonly experience three key factors that make it harder for them to access services:

- **Vulnerabilities:** Indigenous Australians experience significantly higher rates of disability, homelessness, co-morbidities, and early onset dementia<sup>19</sup>. These increased vulnerabilities inhibit the MAC application process because they correlate to decreased education, capacity and resources, which makes it harder to use a system that requires people to have computer and internet access and literacy, and phone access.
- Racism: Indigenous Australians have experienced significant racism historically and still today, both from government institutions and policies, and from Australian society in general. This makes it difficult to trust government systems like MAC, and means Indigenous people begin the application process from a position of being concerned they will experience more racism (even to the extent of removal from Country, institutionalization, incarceration and/or abuse, based on previous experiences of racist government policies historically) if they engage with this process, so they commonly avoid engaging.
- Complexity of need and trauma: Indigenous Australians are recognized as experiencing complex needs and trauma, particularly the Stolen Generations. This commonly involves a distrust and fear of government processes, and processes that could lead to institutionalisation by the government in the name of providing care. This results in people commonly choosing not to apply for aged care services that they need. In other cases, people do apply and then experience racism or a lack of cultural safety in interactions with systems and staff who have not undergone cultural safety training, or who assert racist ideas or assumptions, which then deters these people from progressing their application or engaging with the system in future.

Complex needs and trauma also commonly result in people needing a range of coordinated care and support, such as healthcare for chronic disease, disability support, and social and emotional wellbeing supports. This complexity of need is commonly not accurately assessed by non-Indigenous staff, staff who have not had cultural safety training, and by the system in general which does not cater to the needs and sensitivities of Indigenous Elders.

Regarding the distrust of aged care services cited in this and the previous dot point, IUIH has found that once people have established trust in a provided (usually through engaging a low-level of care), the services they require and request commonly escalates significantly at the stage of the second care plan review. At this point, people commonly divulge much more extensive and intimate details of their ill-health and/ or disability, because the assessor and provider they have been engaging with have earned their trust.



There are four key aspects of the current My Aged Care (MAC) application and assessment process that commonly inhibit access, and result in incorrect assessments for Indigenous Australians:

- Accessibility: The MAC system and application process require people to have computer and internet access and literacy, and phone access. This impedes many older Australians, especially Indigenous Australians, from completing an application because they experience higher rates of disability, homelessness, co-morbidities, and early onset dementia<sup>20</sup>.
- **System design:** The Royal Commission into Aged Care Quality and Safety Interim Report found that eligible Australians consistently found the MAC website and process to be "frightening, confronting and confusing", requiring incessant assessments that are exhausting and upsetting due to repetition and lack off navigation support, and then leaving them with limited choices of service providers due to "inflexible system design, lack of services near where they live, and cost." At this point, it is uncommon that they will be given useful information or find assistance within the system<sup>21</sup>. This is how hard it has been found for non-Indigenous Australians and their families to navigate access pathways in the current system. Given the added vulnerabilities and apprehensions of Indigenous Australians, it is even harder for them to access services through this system.
- **Navigation:** The MAC system does not ensure equitable access, because it does not account for the varying capacities of people to access and navigate the application process<sup>22</sup>. Culturally safe navigation supports would assist people to navigate the application process, but are not available, nor made available by Commonwealth government funding. This is despite government acknowledgment of the difficulties experienced in navigating the system<sup>23</sup>.
- Cultural safety and trauma informed: The assessment process is not culturally sensitive to the complex trauma and history of racism experienced by Indigenous Australians, particularly the Stolen Generations. This is because cultural safety training is currently not mandatory for assessors (ACAT or RAS), and having Indigenous assessors is not mandatory for service providers. Engaging with the online application, and often engaging with assessors by phone or in person, exposes people to questions and staff that have not been qualified by cultural safety training and principles. This means access pathways make people vulnerable to re-traumatisation, and incorrect assessment, which commonly deters people from applying.

Lack of culturally safe assessors also results in access to necessary services being inhibited by assessors not getting a comprehensive understanding of a persons' needs. This is due to the fact that assessors commonly do not understand the specific needs of the person and their Community (which can be very different to non-Indigenous people with the same affliction due to Indigenous communities needing 'family centered care' instead of 'person centered care' to accommodate their needs<sup>24</sup>); and/ or are commonly not told all the information by the patient because they cannot trust a non-Indigenous assessor due to negative past experiences with mainstream services and government policies.



Lack of cultural safety impedes people living in urban and regional areas as much as it does those living in remote areas in accessing mainstream aged care and health services. Less than 20% of eligible Indigenous people live in remote areas, yet the focus of government policies and media attention has been and remains on improving access for remote communities<sup>25</sup>. The number and proximity of mainstream aged care services is not an adequate measure of service accessibility for Indigenous people. Although cultural safety is considered a major barrier for remote communities, there is no focus on lack of cultural safety being a significant barrier for the more than 80% of eligible people who do not live remote areas.

Given that urban Indigenous communities carry similar lifespan gaps, equal levels of multiple chronic diseases, equally high dementia rates, and equivalent social disadvantage to remote communities<sup>26</sup>, this means that the system does not focus sufficiently on enabling access for the vast majority of this cohort.

#### **In-home care**

In-home care enables people to live at home for longer. Most people have a strong preference to staying at home as it allows them to maintain independence, and connections to their family and local Community. For Indigenous Australians, receiving adequate in-home care (and the government funding to enable that support) enables them to stay on Country, which is profoundly important to their spiritual, emotional and mental health<sup>27</sup>.

There are, however, fewer Indigenous Australians over 50 years of age on Home Care Packages (HCP) than:

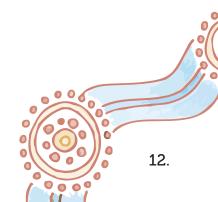
- their non-Indigenous counterparts: there are 3,361 Indigenous people on Home Care Packages (including all levels, 1-4), compared to 127,682 non-Indigenous people on home-care packages (including all levels, 1-4)<sup>28</sup>.
- there should be given the level of need of this cohort, as indicated by their experience of significantly higher rates of disability, homelessness, co-morbidities, and early onset dementia than the non-Indigenous cohort<sup>29</sup>.

There are many more Indigenous Australians on Commonwealth Home Support Packages (CHSP) than are on HCP which has higher co-payment costs and necessitates more stringent, in-depth and accurate assessments for a person to qualify:

20,198 people on CHSP, and 3,361 people on HCP<sup>30</sup>.

The factors inhibiting accurate assessment discussed in the above section regarding access pathways could explain this significant difference between Indigenous people on CHSP and HCP, given that a higher rate in chronic illness and disability would suggest this cohort should have a higher representation on HCP, not CHSP.





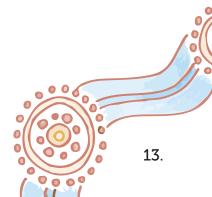
There are also fewer Indigenous Australians over 50 years of age on CHSP than:

- their non-Indigenous counterparts: there are 20,198 Indigenous people on CHSP, compared to 762,845 non-Indigenous people on CHSP<sup>31</sup>.
- there should be given the level of need of this cohort, as indicated by their experience of significantly higher rates of disability, homelessness, co-morbidities, and early onset dementia than the non-Indigenous cohort<sup>32</sup>.

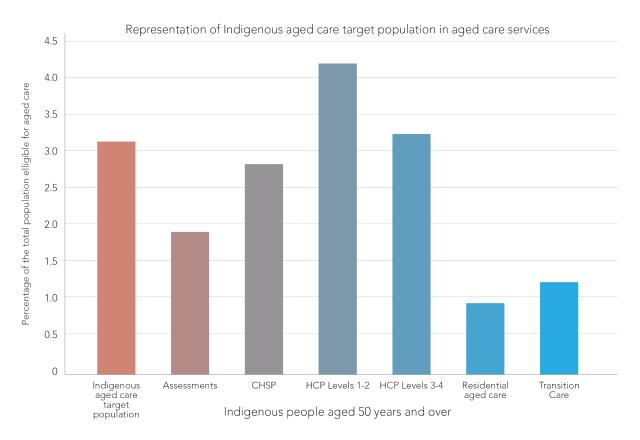
There are five reasons why Indigenous Australians do not currently receive, or receive adequate / inappropriate, in-home care support from the aged care system:

- Access pathways: They are inhibited by the issues in access pathways discussed in the previous subsection.
- Incorrect assessment: Incorrect assessment results from factors such as the lack of cultural safety training for assessors and lack of Indigenous staff, which results in an inability of people to trust assessors and divulge all relevant information and an inability of assessors to fully understand the person's needs in the context of their Aboriginality and Community. Indigenous people are consequently commonly assessed incorrectly, such that they are allocated a lower level support package than what they really need. This is evidenced by the higher rate at which Indigenous people are allocated Commonwealth Home Support Packages (CHSP) and lower level (i.e. level 2) Home Care Packages (HCP), which is inconsistent with the higher rate of need of this cohort.
  - o 70.6% of all Indigenous people receiving some level of aged care services are on CHSP, compared to 59.2% of all non-Indigenous people.
  - o Indigenous people represent 4.2% of all Australian recipients of either a level 1 or 2 HCP. In comparison, they represent only 3.2% of all Australian recipients of either a level 3 or 4 HCP.

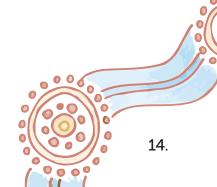




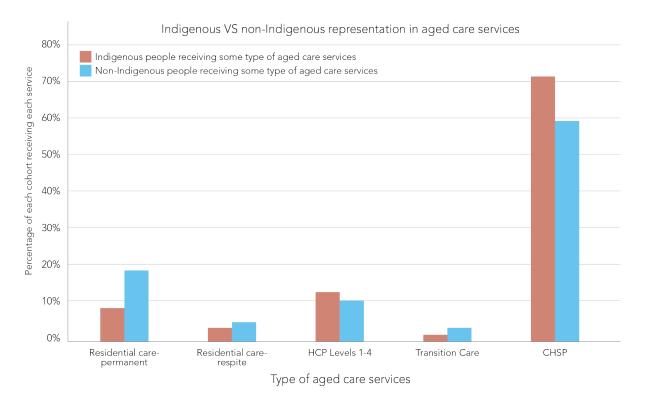
The graph below shows that the representation of the Indigenous cohort in higher, more expensive levels of care is not consistent with the size of the cohort (3% of total Australian population eligible for aged care services), let alone the higher rates at which this cohort experience chronic illnesses. Indigenous people are more commonly allocated a lower level HCP packages, or CHSP which offers lower level support. As a population, they have lower rates of HCP (levels 3-4) than HCP (levels 1-2) and significantly lower levels of assessments, residential care and transition care.







The graph below shows that Indigenous people are significantly more commonly allocated CHSP support than any other level of care. While the non-Indigenous cohort is also significantly more commonly allocated CHSP support than any other aged care service, this cohort still has a significantly higher representation in residential care (both permanent and respite) and transition care. The Indigenous cohort have a higher representation in HCP and CHSP.



Note: the vertical access indicates the percentage of each cohort, where the 'cohort' is the number of people who are currently receiving some kind of service (i.e. not the 'cohort' as the total population of Indigenous or non-Indigenous people eligible for aged care, as per the rest of this report).

- There are 20,198 Indigenous people on CHSP, which is 70.6% of all Indigenous people receiving some level of aged care services.
- There are 3,361 Indigenous people on HCP, which is 11.8% of all Indigenous people receiving some level of aged care services.
- There are 762,845 non-Indigenous people on CHSP, which is 59.2% of all non-Indigenous people receiving some level of aged care services.
- There are 127,682 non-Indigenous people on HCP, which is 9.9% of all non-Indigenous people receiving some level of aged care services.



- System design: The difference in payment requirements between lower and higher levels of support also contributes to Indigenous people, who on average present with significantly lower economic indicators of financial security and prosperity<sup>33</sup>, being allocated lower levels of in-home care than they require. CHSP has variable or absent fees depending on the patient/client's financial capacity and the fees policy of the provider<sup>34</sup>. In contrast, the higher levels of care available on HCP have co-payment requirements, based on the idea that patients/clients should share the costs of their care with the tax-payer (i.e. through government subsidies) to the extent they are financially able, which is determined by an income-assessment<sup>35</sup>. That premise is fair, but can result in higher level packages being inaccessible to people with high levels of need and low levels of financial capacity to satisfy the co-payment requirements<sup>36</sup>. Indigenous Australians are not the only people who commonly cannot afford this, but they do experience, on average, significantly lower levels of household income over their lives than the non-Indigenous population<sup>37</sup>. This suggests that Indigenous Australians over 50 years of age are less able on average to afford the co-payments required to access the higher level of government support packages, despite on average needing more support.
- Culturally safe and appropriate options: For Indigenous Australians, maintaining connection to Country and kin (which is a broader concept of family than non-Indigenous people generally have) is profoundly important to their spiritual, emotional and mental health<sup>38</sup>.

To this end, they generally want to be cared for by Indigenous staff, because they feel safe with them, they trust them, and they know that local Indigenous staff will understand the context of their Aboriginality and family, and how this determines the kind of services and support they need. Part of this is that Indigenous people want 'family-centered care', as opposed to the 'person-centered care' the system is designed to provide, based on the majority needs of non-Indigenous Australians<sup>39</sup>. They also want to maintain connections to Community and attendance at Community events, such as sorry business and family business. These connections are better enabled by Indigenous staff, who understand their culture and Community responsibilities and identity, and so understand what they need and how to facilitate this.

These options are not available from mainstream in-home care providers, due to: the absence of a viable Indigenous workforce (See section four of this report); lack of quotas for providers to employ Indigenous staff, or to make them available to Indigenous people through brokerage relationships with Indigenous health organisations or aged care providers; cultural safety training not being mandated for providers by the government, and therefore staff rarely having access to this training which is essential to provide equitable access for Indigenous people.

• Funding: see 'funding model' section below



#### Residential aged care

For Indigenous Australians, receiving trauma informed, culturally safe residential care (and the government funding to enable that support) enables them to maintain connection to Country, family and Community, which is profoundly important to their spiritual, emotional and mental health<sup>40</sup>.

There are, however, fewer Indigenous Australians over 50 years of age on residential care packages (permanent and respite) than:

- their non-Indigenous counterparts: there are 2,986 Indigenous people on residential care packages, compared to 300,730 non-Indigenous people on residential care packages<sup>41</sup>. This means 10.4% of the Indigenous cohort currently receiving services are receiving residential care, while 23.3% of the non-Indigenous cohort currently receiving services are receiving residential care.
- there should be given the level of need of this cohort, as indicated by their experience of significantly higher rates of disability, homelessness, co-morbidities, and early onset dementia than the non-Indigenous cohort<sup>42</sup>.

There are four reasons why Indigenous Australians do not currently receive, or receive adequate / inappropriate, residential care from the aged care system:

- Access pathways: They are inhibited by the issues in access pathways discussed in the previous subsection.
- **Incorrect assessment:** As per the explanation for in-home care detailed above, but in this case, people are often assessed as needing low-level in-home care, when in fact their needs require a high level of care that is often consistent with residential care.
- System design: As per the explanations for in-home care detailed above.
- Culturally safe and appropriate options: As per the explanations for in-home care detailed above. Regarding maintaining connection to Country and kin, the necessary options (such as being cared for by Indigenous staff, remaining connected to Country<sup>43</sup>, or cultural sensitivity) are not available in mainstream residential facilities, and people tend to "self-isolate and die earlier" as a result<sup>44</sup>.

A demonstrative instance of cultural insensitivity was when a Quality and Safety Commission assessment officer, undertaking an audit of a residential provider facility, determined a cultural artifact was a risk and directed that they be locked away from residents. This artifact was of great cultural and spiritual significance to the Elders residing at that facility. This assessor insisted the artifact (similar to a tomahawk) was an OH&S risk and must be confiscated and stored in a locked box away from the resident Elders. This caused great upset and distress to these residents, for whom the artifact symbolized connection to family, Community and Country despite having to move off Country into a residential aged care facility (Anonymous NAGATSIAC source, 2019). This evidences that assessors who are not trained in cultural safety are unable to navigate and negotiate the requirements of OH&S while upholding necessary principles and practices of cultural safety.



Residential care is particularly associated with institutionalization, which is a huge deterrent for the Stolen Generations in particular, given the abuse and injustice they suffered when institutionalized by the state as minors. It is also a huge deterrent for Indigenous people given the incredibly high rates at which: Indigenous adults are incarcerated at relative to non-Indigenous adults (as of June 2018, Indigenous adults account for 28% of the total adult Australian prison population<sup>45</sup>); Indigenous youth are incarcerated relative to non-Indigenous youth ("On an average night in the June quarter 2018, nearly 3 in 5 (59%) young people aged 10–17 in detention were Indigenous, despite Indigenous young people making up only 5% of the general population aged 10–17"<sup>46</sup>); Indigenous children and youth are forcibly removed from families on child protection orders, despite there being no data to suggests they are safer or healthier once removed than if left in their families ("The South Australian Child Protection Systems Royal Commission concluded in 2016 that the risk of sexual abuse in out-of-home care "has not diminished" and action to address it is "long overdue". And the Royal Commission into Child Sexual Abuse acknowledged the extent of abuse in out-of-home care nationwide remains unknown"<sup>47</sup>).

• Funding: see 'funding model' section below

### **Funding model**

The way residential and in-home care services are currently funded is a contributing factor to the lower rates of Indigenous Australians over 50 years of age applying for and receiving aged care services when they need them.

Aspects of the funding model serve as barriers to Indigenous Australians in accessing and receiving appropriate levels of care:

- Limited urban funding, limited NATSIFACP: The National Aboriginal and Torres Strait Islander Flexible Care Program (NATSIFACP) is currently generally limited to remote regions. It provides a stable funding base that enables small ACCO facilities with limited economies of scale to cover fixed costs. This is crucial to enabling ACCOs to operate and provide aged care services. 80% of all Indigenous Australians live in urban and regional areas<sup>48</sup>, and 80.3% of Indigenous Australians aged 50 years and over, i.e. eligible for aged care services, live in urban and regional areas<sup>49</sup>. This means that NATSIFACP funding being limited to remote areas precludes 80.3%, which is the vast majority of this cohort, from having access to ACCO aged care services, which are not only their preference but the most culturally safe and trauma informed.
- **Insecure funding:** There is a lack of long-term, secure government funding available to ACCO aged care providers makes it economically unviable for them to provide services that they are best placed and equipped to provide in a culturally safe, trauma informed way. This means there is limited, if any, access to services that are culturally safe, trauma informed, and staffed by Indigenous assessors and carers.
- Insufficient funding: Insufficient government funding that is long-term, stable and flexible, to ACCO health services. This is necessary for ACCOs to be able to provide a level of care (on in-home care packages) that is not limited to basic support. This means that there is limited, if any, access for Indigenous people needing high levels of care (which is a significant proportion of people, given the significantly higher rates



- of co-morbidities and disability that this cohort experience than their non-Indigenous counterparts) to services that are culturally safe, trauma informed, and staffed by Indigenous assessors and carers.
- Mixed funding models / block funding: There is a lack of mixed funding models, and a particular lack of models including block funding, provided to ACCHOs on a long-term basis. This is especially debilitating to small ACCOs. Block funding is needed to supplement individualized care packages, and residential aged care funding based on ACFI. This model of funding ensures the fair distribution of funds across the organization, so that all aspects of service delivery are adequately resourced. This is essential to ensuring their economic viability now and in the future.
- Insufficient investment in a sustainable Indigenous workforce: Insufficient funding for training and recruitment of more Indigenous Australian staff to meet the current and growing cohort of Indigenous people needing aged care services (as the population of eligible Indigenous Australians grows).
- Insufficient investment in culturally appropriate screening tools: Mainstream providers are not equipped with the necessary tools to provide culturally appropriate assessments for Indigenous people. For example, the Kimberly Indigenous Cognitive Assessment (KICA) screening tool has been validated for use in a range of Indigenous communities<sup>50</sup>.

The features of the funding model listed above also exacerbate other factors that already inhibit Indigenous Australians to access and receive appropriate levels of care.

The funding model does not enable, and in many ways impedes and prevents ACCOs from being able to provide aged care services. ACCOs are best placed to deliver aged care services to Indigenous people, because they do not experience the issues discussed in the previous section regarding access pathways, in-home care and residential care that deter Indigenous engagement. Therefore, by inhibiting ACCOs from providing services in an economically viable way, the current funding model inhibits access and delivery of services in a way that would enable this cohort to engage with the system.

The way aged care services are currently funded precludes equitable access to appropriate levels of care for Indigenous Australians.



# 3. Likely roadblocks

## What would a culturally sensitive aged care system would look like?

NAGATSIAC believes that minimum targets for Indigenous employment within service providers, relative to Indigenous population of their catchment area, would enable an increase in the Indigenous workforce. This would in turn increase the capacity of service providers, as well as incentivising them, to provide the option to people of being assessed and / or cared for by Indigenous staff. This presents two possible roadblocks:

- a perceived conflict of interest between Indigenous assessment providers, and Indigenous service providers
- the lack of an established, Indigenous workforce with the capacity to meet the demand of the Indigenous cohort needing assessment and services.

#### Perceived 'conflict of interest'

This has the potential to raise concerns regarding possible conflicts of interest, in circumstances where Indigenous assessment services then refer people to Indigenous service providers, which could even be provided by the same ACCO/ACCHO.

This possible perception of a conflict of interest presents a significant roadblock to policies to promote culturally safe, trauma informed aged care services to Indigenous people, and to the establishment of an economically viable Indigenous workforce in this sector and economically viable Indigenous aged care service providers.

This roadblock results from a lack of a culturally sensitive perspective within government policy and can be overcome by incorporating an understanding of what choice and equitable access means within the current system and its economic and logistical limitations for Indigenous health services and aged care providers.

What does 'choice' and self-determination mean for Indigenous Elders needing aged care services?

- Culturally safe, trauma informed assessment and services can be most effectively and
  efficiently provided by Indigenous organisations and staff. This is also known to be the
  preference of Indigenous people seeking aged care services.
- People have a right to choose services and providers that suit them. For Indigenous people, there is commonly no option of culturally safe providers in their area because there are not many culturally safe or Indigenous providers in the market. To afford choice to Indigenous people necessitates the establishment of a culturally safe, trauma informed workforce that employs enough Indigenous staff to fulfil Indigenous client/patient's preferences to be assessed, and cared for, by Indigenous staff.
- There are few Indigenous assessors, and few Indigenous service providers. It is currently common for Indigenous people to not have access to any Indigenous staff through MAC assessment or service providers. If they have access to Indigenous assessment staff, then it is not a given that they have access to any Indigenous service providers,



- and if they do, it is commonly the same Indigenous organization providing assessment and services.
- There are two options to avoid the perceived 'conflict of interest' in an Indigenous health service and/or aged care service referring patients/clients to either their own services, or the services of another Indigenous organization.

First, recognize that given the significant underrepresentation of Indigenous staff and services in the sector, it is not logical or ethical to disallow Indigenous assessors from referring Indigenous people to other Indigenous health and aged care providers. This is not a conflict of interest. Rather, it is the provision of choice to Indigenous clients/patients, in the same way that non-Indigenous providers can and do refer non-Indigenous clients/patients to the providers that they prefer, and that are close to their homes and families.

Second, redesign the aged care system so that it enables the recruitment, training and stable employment of a culturally safe, trauma informed, Indigenous workforce that can provide the care Indigenous people want, need, and have the right to choose as their first preference.

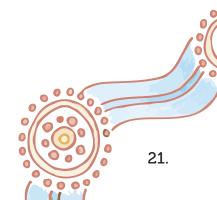
#### Indigenous workforce

The current aged care system inhibits the establishment, by Indigenous health services and aged care services, of a stable and economically viable Indigenous workforce that has the capacity to meet the demand of the Indigenous cohort needing assessment and services.

This is largely due to the lack of culturally safe policies and practices in the sector, and to the problematic funding model (discussed in section 2) which often inhibits ACCO providers of aged care and health care from becoming economically viable and able to expand in the current system. These two factors combine to offer a coordinated solution: Adjust the funding model of the aged care system so that it enables ACCOs, who can then build and operate an Indigenous workforce who are best able to provide culturally safe aged and health care.

The impending system redesign must enable the aged care system to establish a culturally safe, trauma informed, Indigenous workforce to provide the care Indigenous people want, need, and have the right to choose as their first preference. Options for doing so are discussed in detail in the accompanying NAGASTIAC paper: 'Our Care. Our Way: Transforming care pathways for Aboriginal and Torres Strait Islander Elders'.





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- 6. For example, the Australian Bureau of Statistics 2015 Survey of Disability, Ageing and Carers (SDAC) SDAC is the most comprehensive and recent collection of disability data but was not designed to collect disability data for the Aboriginal and Torres Strait Islander population specifically. As a result, the SDAC provides robust national level statistics, but has limitations when disaggregating for the Aboriginal and Torres Strait Islander population. Also, the SDAC did not collect data from very remote areas and is limited in its geographic output.

  Australian Bureau of Statistics, '2015 Survey of Disability, Ageing and Carers (SDAC)', ABS (online) <a href="https://www.abs.gov.au/ausstats/abs@.nsf/">https://www.abs.gov.au/ausstats/abs@.nsf/</a> mf/4430.0>
- 7. This is the most conservative estimate of need. This number is used because it accounts for the total known need of this cohort. This figure includes:

All people approved for a Home Care Package (HCP) which includes:
o people approved for an HCP which has not yet been allocated, nor have they yet been offered a lower level 'interim' package (69,086) (as at 30 September 2018)

o people who have been approved and allocated an 'interim' package which is lower level than their assessed needs o people who have been approved and allocated an HCP which is consistent with their assessed level of need.

Lack of a centralized waiting list for CHSP and residential care means that it is difficult to access reliable data on people who need but are unable to access these services. These people are not included within this number, and are:

 people who have been assessed as eligible for residential care who are yet to find a facility with capacity to accommodate them
 people who have been assessed as eligible for services funded by CHSP who have not yet found a provider who capacity to provide their service.

Number of people awaiting their approved level package at 30 September 2018, yet to be offered a lower level package: Department of Health, 'Home Care Packages Program Data Report 1st Quarter 2018-2019', Australian Government (online), November 2018 <a href="https://gen-agedcaredata.gov.au/www\_aihwgen/media/Home\_care\_report/HCP-Data-Report-2018%E2%80%9319-1st-Qtr%E2%80%93.pdf">https://gen-agedcaredata.gov.au/www\_aihwgen/media/Home\_care\_report/HCP-Data-Report-2018%E2%80%9319-1st-Qtr%E2%80%93.pdf</a>. p.

Number of clients with services being successfully delivered: Australian Bureau of Statistics, '4430.0 - Disability, Ageing and Carers, Australia: Summary of Findings, 2018', ABS (online), 24 October 2019 <a href="https://www.abs.gov.au/ausstats/abs@.nsf/mf/4430.0">https://www.abs.gov.au/ausstats/abs@.nsf/mf/4430.0</a>.

**8.** This percentage was calculated as follows:  $(a / b) \times 100 = 95\%$ 

(a) Number of non-Indigenous Australians aged over 65 who are currently receiving some kind of aged care services = 1,289,159. This number is from 2017-18 ROGS data.

Productivity Commission, 'Report on Government Services 2018, Part F, Chapter 14), Australian Government (online), <a href="https://www.pc.gov.au/research/ongoing/report-on-government-services/2018/community-services/aged-care-services">https://www.pc.gov.au/research/ongoing/report-on-government-services/2018/community-services/aged-care-services</a>
(b) Number of non-Indigenous Australians aged over 65 who are currently in need of some level of aged care services (assuming non-Indigenous people generally do apply for services when they have a need) = 1,358,245.

This number was calculated by adding value (a) to the number of people awaiting their approved level package at 30 September 2018, yet to be offered a lower level package (69,086).

Commonwealth Department of Health, 'Home Care Packages Program Data Report 1st Quarter 2018-2019', Australian Government (online) <a href="https://gen-agedcaredata.gov.au/www\_aihwgen/media/Home\_care\_report/HCP-Data-Report-2018%E2%80%9319-1st-Qtr%E2%80%93.pdf">https://gen-agedcaredata.gov.au/www\_aihwgen/media/Home\_care\_report/HCP-Data-Report-2018%E2%80%9319-1st-Qtr%E2%80%93.pdf</a>

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Australian Bureau of Statistics, 'Disability, Ageing and Carers Australia (2015)', Australian Government (2015). Custom data.

The burden of disease (per 1,000 of each cohort) of Indigenous Australians over 50 years old is 749.5, while for non-Indigenous Australians over 65 years old, it is 593.2. This is a significant difference of 156.3 per 1,000 people in each cohort.

Australian Institute of Health and Welfare, 'Custom data request: VACCHO IBOD request final', sourced from AIHW analysis of Burden of Dis-

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Mortality: The age-standardised death rate for Indigenous males aged 55-64 years (2011 per 100,000 population) is 3 times as high as for non-Indigenous males. The age-standardised death rate for Indigenous females aged 55-64 years (1466 per 100,000 population) is 3.7 times as high as for non-Indigenous females. Note: this data is not publicly available disaggregated by the specific, different age groups eligible for aged care services in the Indigenous, and non-Indigenous populations (i.e. 50 years, and 65 years). However, we argue that the available data for the age group 55-64 years in each of these two populations is representative for a general comparison, especially given how big the gaps are in mortality for both sexes, between each cohort. Australian Institute of Health and Welfare, 'Life expectancy and mortality of Aboriginal and Torres Strait Islander people,' Australian Government (online, 2011 < https://www.aihw.gov.au/getmedia/5e6b79b6-dbcd-45c6-a4d2-e5b5ce278ebc/12328. pdf.aspx?inline=true> p. 9.

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- **48.** Australian Bureau of Statistics, 'Census of Population and Housing: Reflecting Australia Stories from the Census, 2016', Australian Government (online), <a href="https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/2071.0~2016~Main%20Features~Aboriginal%20and%20Torres%20Strait%20islander%20Population%20Article~12>
- **49.** 24,137 Indigenous people aged 50 years and over live in remote areas, as of the 2016 census. Given the total number of Indigenous people aged 50 years and over as of the 2016 census is 122,600, this means the % of this cohort who do not live in remote areas is 80.3%. This is calculated by subtracting the remote cohort from the total cohort (122,600 24,137 = 98,463 people do not live remote), and then calculating the percentage of the non-remote cohort. Australian Bureau of Statistics, '3238055001DO006\_201609 Estimates of Aboriginal and Torres Strait Islander Australians, June 2016', Australian Government (online), <a href="https://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/3238.0.55.001June%202016?OpenDocument">https://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/3238.0.55.001June%202016?OpenDocument</a>
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