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AMSANT Submission to the Royal Commission into Aged Care Quality and Safety

Preliminary submission

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AMSANT is the peak body for the community controlled Aboriginal primary health care (PHC) sector in the Northern Territory (NT). AMSANT has been established for 20 years and has a major policy and advocacy role at the NT and national levels. We have 25 members providing Aboriginal comprehensive primary health care across the NT from Darwin to the most remote regions, including for many Aboriginal elders. Three of our member services also received funding to provide Aged Care programs, with two of these running the aged care centres in their communities.

The ACCHSs sector in the NT is comparatively more significant than in other jurisdictions, being the largest provider of Aboriginal primary health care services to Aboriginal people in the NT. Around two thirds of all Aboriginal PHC services in the Northern Territory are provided by ACCHSs.

AMSANT have been disappointed by the Commission's decision not to visit any remote communities during their time in the NT. It is vital that the Aboriginal Elders, community members and service providers be provided an opportunity to express the unique challenges they face in aging on country and accessing the necessary and culturally appropriate aged care services and facilities. While we will continue to engage with the Commission, we are concerned that this decision will impact the quality and completeness of evidence.

We have structured our submission in direct response to Terms of Reference a) through g), as set out by the Royal Commission. This is intended to be a preliminary submission to inform the Commission of key issues for the ACCHSs sector ahead of the NT hearings. Feedback gathered from member services highlighted the following as key thematic issues for consideration:

- Funding and resourcing
- External/non-Indigenous service providers and aged care facilities
- Bureaucracy and red tape
- Workforce
- Cultural security
- Aged care patient needs
- End of life care

It is also in the Commission's interest to note that currently the Royal Darwin Hospital is totally full and has cancelled all elective surgery. This is a sign of a system under severe strain and is particularly worrying given RDH is the only tertiary hospital for the whole of the NT. A key reason is bed block due to lack of aged care and disability places. It has been estimated that there are 30 patients awaiting aged care places. The lack of investment in aged care in the NT is putting the whole hospital system at risk.

a) The quality of aged care services provided to Australians, the extent to which those services meet the needs of the people accessing them, the extent of substandard care being provided, including mistreatment and all forms of abuse, the causes of any systemic failures, and any actions that should be taken in response

- There are very limited resources to provide quality aged care in rural and remote locations, particularly in the NT.
- Basic levels of aged care are being delivered effectively (i.e. day care, domestic assistance, simple transport and meals) but it is not feasible to cover complex care needs, respite care and 24 hour care in many communities.
- Shortfalls in the formal Aged Care system are often picked up by the PHC sector.
- Aboriginal community controlled services are not for profit and struggle to compete with the economies of scale of large providers (either for profit or not for profit). However, community controlled services are much more likely to provide culturally appropriate services, including in hard to reach locations, and employ and retain local people.
- High turnover and lack of specialised staff in rural and remote settings compromises continuity of care and the building of strong therapeutic relationships between carers and elderly patients, which are so vital to Aboriginal people. This could be greatly reduced by a strategy of enhancing local employment.

b) How best to deliver aged care services to:

i. people with disabilities residing in aged care facilities, including younger people; and

ii. the increasing number of Australians living with dementia, having regard to the importance of dementia care for the future of aged care services

People living with a disability

- Intersection between the Aged Care system and the NDIS is a real challenge along with an unrealised opportunity for joint initiatives in workforce development, capacity building and economies of scale/efficiencies in provision of specialist services.
- Both systems rely on an individual and consumer-driven market mechanism that does not enable the best outcomes for Aboriginal people.
- Lack of services and infrastructure in remote areas has resulted in instances where NDIS and Aged Care patients are being co-located. This is often inappropriate.
- NDIS providers face many of the same challenges regarding workforce training, retention and ensuring cultural security for patients that are faced by Aged Care service providers.

People living with dementia

- There is a growing need for dementia care in the NT, with an estimated 1764 people living with dementia, which is expected to increase to over 2700 in the next 10 years[1].
- Among 45 to 69 year olds, it has been suggested that Aboriginal people are twenty times more likely to have dementia than their non-Aboriginal counterparts[2]
- We need to ensure access to public dental services due to the high prevalence of gum disease among this group.

Recommendation: Increased provision of dementia care services for Aboriginal people with a focus on delivery by ACCHSs and other Aboriginal community controlled providers.

Recommendation: Increased access to public dental services for aged care patients, with a focus on people suffering with dementia.

c) the future challenges and opportunities for delivering accessible, affordable and high quality aged care services in Australia, including:

i. in the context of changing demographics and preferences, in particular people's desire to remain living at home as they age; and

ii. in remote, rural and regional Australia

Particular demographics of the NT

- A rapidly aging NT population will mean increased demand for aged care services. People aged 65 years and over makeup 7.2% of the population, a percentage that has been trending up over the last five years[3]
- Projections estimate that the population of Aboriginal Territorians aged 65+ will increase 340% from 2011-41, compared with 242% for the non-Aboriginal population[4]
- 80% of older Aboriginal people live outside of urban areas[5]
- The NT has the highest share (43%) of NATSIFlex places and is the only jurisdiction with more Home Care than Residential Care places[6]

[1] Dementia Australia (2018), Dementia Prevalence Data 2018-2058, NATSEM, University of Canberra, accessed at: https://www.dementia.org.au/files/documents/2019-2058-Dementia-prevalence-S-T.pdf
[2] House of Representatives Standing Committee (2013), Thinking Ahead, report on the inquiry into dementia: early diagnosis and intervention. Department of Health, Canberra.
[3] ABS, 2016 Census Quickstats, Northern Territory, accessed at: https://quickstats.censusdata.abs.gov.au/census_services/getproduct/census/2016/quickstat/7?opendocument
[4] Industry Skills Advisory Council NT, NT Industries: Aged Care, accessed at: https://www.isacnt.org.au/NT-industries/aged-care
[5] Lowe, M. and Coffey, P. (2019), Effect of an ageing population on services for the elderly in the NT. *Australian Health Review,* 43, 71-77.
[6] Industry Skills Advisory Council NT, NT Industries: Aged Care, accessed at: https://www.isacnt.org.au/NT-industries/aged-care

- Aboriginal people access aged care services from a younger age, with AIHW reporting 1 in 4 (26%) Indigenous Australians in care aged under 65, compared with 3% of non-Indigenous Australians[7].
- Older Aboriginal people are also more likely to experience complex chronic disease and other markers of disadvantage.
- The importance of connection to country and kin creates specific needs in relation to elderly Aboriginal people seeking to age at home and on country.

Challenges of remote service delivery

- There is limited capacity for high level aged and disability care remotely.
- There is a lack of housing in remote communities, including for staff accommodation. Current funding models do not allow for expenditure on infrastructure, instead services must apply for grants. Despite a significant level of need we have been told by a number of member services that grant applications made recently for funding toward infrastructure have been unsuccessful.
- There is not enough resourcing to adequately cover transport costs. For example, the bush bus is not appropriate to take someone needing high level care to town for an appointment.
- Remuneration is not high enough to attract quality staff to regional and remote locations. A lot of resources are expended training new staff when there is high turnover. Opportunities for training local Aboriginal staff in Aged Care careers offer an important solution to these challenges, providing improved staff retention and cultural responsiveness.

d) What the Australian Government, aged care industry, Australian families and the wider community can do to strengthen the system of aged care services to ensure that the services provided are of high quality and safe

Aged Care Programs

- An individualised, consumer and market-driven system is does not work in the context of the NT where there is little or no market and is also not culturally appropriate and likely to disadvantage Aboriginal people even in urban areas. Elderly clients are often not in a position to advocate on their own behalf, and this is compounded when people do not speak English.
- Multiple funding streams through CHSP, Home Care Packages and NATSIFlex creates complexity in eligibility and reporting and an unnecessary administrative burden.
- The current system does not support allied health services to be used effectively across NDIS, aged care and primary health care in order to make them sustainable and efficient. This is causing wastage and inefficiency as well as contributing to a lack of services.

[7] Australian Institute of Health and Welfare (2018). National Aged Care Data Clearinghouse: AIHW analysis of unpublished data.

- The cap on the total number of packages available per jurisdiction, and the allocation of a certain number of packages to each level of care package creates unacceptable wait times, as well as challenges to effective service delivery when funds cannot be pooled.
- NATSIFlex funding allows organisations to provide more culturally appropriate aged care to older Aboriginal people close to home and community through a block funding model, based on an agreed allocation of places. This provides a constant income stream so that the service provider has both the stability of income from the funding and the flexibility to manage the delivery of aged care services to meet the needs of the community.
    - An application for NATSIFlex funding from one of AMSANT's very remote member services, who already provide home care packages, was knocked back on the basis of the quality of their application. This is a service effectively providing NDIS and aged care to a homelands population who are otherwise likely to completely miss out. Grant applications are onerous processes for smaller services like this, and this example clearly demonstrates that administrative processes are acting as a barrier to access, particularly in high-need disadvantaged populations.
- Funding provided through Aged Care packages is not sufficient to meet the complex needs of patients, particularly those with complex needs.
- Arduous and exacting accreditation processes for facilities are a major hurdle to establishing residential facilities in rural and remote settings where potential providers are likely to be smaller organisations with more limited capacity.
- There is no effective cultural accreditation for mainstream nursing providers.
- Assessment processes are slow, inadequate and can be confronting and distressing for patients.
    - Members report waits of up to 18 months to get an ACAT review, and further wait time for home care packages even after assessment.
    - One of AMSANT's member services reported an incident where one of their patients became so distressed by personal questions during a RAS assessment being conducted over the phone that they walked out and refused to continue.

Recommendation: That flexible block funding, like that available through NATSIFlex, be considered the standard for delivery of Aged Care services to all Aboriginal people.

Recommendation: That assessment processes be decentralised to reduce wait times and allow for more person-centered and culturally appropriate processes.

Recommendation: That mechanisms be considered to enable allied health and other specialist services to be used effectively and efficiently across NDIS, aged care and primary health care in order to provide cost effective services

Community-control and cultural safety

- Building the capacity of community-controlled organisations is central to the goal of culturally appropriate service delivery.

- Employing appropriate levels of Aboriginal staff is vital to achieving a culturally safe environment. AMSANT member services have raised concerns that some mainstream/non-Indigenous service providers do not employ local people and that there are concerns regarding adequate training in cultural safety.
- To grow a local workforce will require sustained investment in training and support, attractive salaries and a flexible, culturally responsive working environment. Much more investment is needed to support Aboriginal people in remote areas to obtain basic literacy and numeracy so that they can progress from entry level roles. This would assist in developing a workforce across NDIS, aged care, primary health care and other social services. There then needs to be sustained appropriate support through formal training. Community controlled organisations have a much better record of employing and retaining local workforce compared to mainstream organisations.
- The ability to communicate effectively in a person's first language and to be heard by someone with a cultural understanding is an important element of cultural safety. This is particularly important for elderly people who often revert to their first language in their later years.
- Investing in local community-controlled organisations is necessary to ensure that more Aboriginal people can continue to age at home and on country. Currently a large portion of Aboriginal people must move to regional centres for care because their needs cannot be managed in their home communities. These people can become quite isolated and distressed.

Recommendation: That relationships between aged care service providers and community controlled health services be further developed, in particular by creating stronger links between the delivery of CHSP and Home Care Packages and domiciliary nursing provided through Primary Health Care services.

Recommendation: That there is greater investment in training Aboriginal staff across aged care and disability with appropriate support for numeracy and literacy followed by mentoring and support through formal training provided on country or near to country wherever possible.

e) How to ensure that aged care services are person-centered, including through allowing people to exercise greater choice, control and independence in relation to their care, and improving engagement with families and carers on care-related matters

Responding to the needs of Aboriginal people

- Must ensure that standards and regulations are appropriate for Aboriginal people and support the quality of life of aged care clients including through practices such as yarning time around fire pits, access to traditional foods, supporting options for outside living, return to country trips etc.

Advocacy

- Currently the National Aged Care Advocacy Program (NACAP) is provided through a single, national provider called the Older Persons Advocacy Network (OPAN). In the Northern Territory, OPAN contracts advocacy services for the Top End to the Darwin Community Legal Service and to Catholic Care for Central Australia.
- Community guardians have high caseloads and don't visit patients often enough to advocate for them in a timely fashion.
- Need to re-establish the former Commonwealth Aged Care Advocacy Service, with an Aboriginal-specific aged care advocate funded within AMSANT for the NT.

Recommendation: Aged Care Advocacy Services should be re-established. Regionally based and Commonwealth funded, these advocacy services should provide a culturally appropriate and accessible complaints process.

f) How to deliver aged care services in a sustainable way, including through innovative models of care, increased use of technology, and investment in the aged care workforce and capital infrastructure

Addressing the social and cultural determinants of health

- Social and cultural determinants are considered to account for between one third and one half of the gap in health status between Indigenous and non-Indigenous Australians. In particular, frail and elderly Aboriginal people are often living in very substandard overcrowded housing which makes effective service provision very challenging.

Investing in comprehensive PHC

- Aboriginal people have much higher rates of dementia, stroke and other disabling conditions which in turn are caused by high rates of chronic disease as well as poor social determinants and intergenerational trauma.
- Need to invest in health services across the lifespan as a preventative measure and to ensure people can live in the community for as long as they wish
- Must have a focus on the prevention and treatment of chronic conditions
- Need for integrated, multidisciplinary care

Up-scaling facilities and services to clusters of communities

- It may be feasible to build facilities (and scale-up services) among clusters of communities by pooling funds etc. Surrounding communities can provide workers, volunteers and resources. The efficiency of scale of more residents and larger facilities may make residential care feasible in these locations.

g) Any matter reasonably incidental to a matter referred to in paragraphs (a) to (f);

End of life care

- End of life care uses a Western cultural paradigm of individual autonomy that does not match the traditional collective decision-making of Aboriginal people where family and the community participate in these deliberations.
- Health and Aged Care services should be supported and resourced to ensure wherever possible they can provide the option of end of life care to be managed at home and on country if that is the patient's wish.
- Advanced care directives (ACD) are the only guide on end of life care, and while all people in an aged care residency require an ACD, they need to be properly resourced if it is to be undertaken otherwise there is a real risk that it will not reflect the wishes of the person and family. Many Aboriginal people in nursing homes are also relatively young and may have disabling conditions rather than progressive conditions like dementia.
- For those who are not fluent in English, an Aboriginal interpreter is a must and it is also essential that the right family members are present when an ACD is developed. However, accessing Aboriginal interpreters is difficult and there is no funding to bring family in to nursing homes for this purpose. Aged Care homes in general do not have video conferencing services for residents. This is of particular concern when end of life care needs to be discussed with family that cannot attend in person (especially those members living remotely). Collective decision-making is an important aspect of Aboriginal health and should be facilitated as much as possible. However for these important conversations, there should be funding available to enable family to be present with their loved ones rather than relying on video technology.
- ACDs should be undertaken when the system is working to support the persons' quality of life. A person living in a mainstream aged care facility with no family or cultural support may make a different decision compared to if they were living on country or even if they were living in a regional nursing home with good cultural support (including Aboriginal staff and culturally appropriate non-Aboriginal staff) and regular visits from family. For residents who must live of country, consideration needs to be given to funding to bring family in for visits, support for video conferencing with families and when possible trips back to country.

Recommendation: Advanced Care Directives should be supported with funding for:

1) interpreters;

2) family inclusion in the process including cost of flights and transport from remote communities for families; and

3) training for PHC staff.

Recommendation: Residential aged care should have systems in place to incentivise and support culturally appropriate care for Aboriginal people, including cultural safety being part of accreditation and funding support for cultural activities. Aboriginal people living off country should be supported through funding to allow family to visit, video conferencing to enable regular contact and funded trips back to country where possible.