Submission to the Royal Commission on Aged Care Quality and Safety

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DCLS operates on Larrakia country. We acknowledge the Larrakia people as the Traditional Owners of the Darwin region and pay our respects to Larrakia elders past and present. We are committed to a positive future for the Aboriginal community.

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About Darwin Community Legal Service

DCLS is a multi-disciplinary service providing general legal advice and assistance, a tenancy advice service, and a specialised Seniors and Disability Rights Service providing advocacy support in the areas of ageing and disability. We create awareness and empower our community, support access to services and rights, and advocate for change that promotes fairness and justice.

The Seniors and Disability Right Service recently played host to an Elder Abuse Prevention Project which raised awareness of elder abuse and identified strategies to protect senior Territorians from experiencing elder abuse.

The Seniors and Disability Rights Service employs one full-time and one part-time aged care advocate to service the whole of the Top End of the Northern Territory (NT). Our effectiveness is impacted by limited resources and limited availability of services.

The Seniors and Disability Rights Service assists, and can advocate for, older people or people with disabilities and their representatives to:

- Understand their rights through information and community education
- Receive aged care services or disability support
- Engage with the Guardianship process
- Develop Advance Personal Plans or Powers of Attorney
- Raise systemic issues

Executive Summary

The Royal Commission into Aged Care Quality and Safety is long overdue, and we acknowledge the importance of these issues in safeguarding a highly vulnerable part of the Australian community.

However, we are concerned that undue focus on poor conditions and abuse of elderly people in established aged care facilities will divert attention from a far more fundamental problem. For older people in the Northern Territory (NT), particularly Aboriginal and Torres Strait Islanders living in remote areas, the services simply do not exist. Expenditure on aged care services per person in the NT is the lowest of all Australian states and territories, despite the fact that special needs groups dominate the aged care target population in the NT.[1]

Aboriginal people form a significant part of our clientele (as they do for all mainstream services in the NT) and have the most complex and immediate needs. Therefore, part of this submission focuses on the challenges for Aboriginal people and those living in remote and regional areas of NT in accessing the aged care system and aged care services. If those most in need are unable to access support, then the aged care system is not delivering.

The NT faces unique challenges in service delivery including the tyranny of distance, the lack of infrastructure, high costs relative to other jurisdictions, and the lack of economies of scale. Over 26% of the NT population identifies as Aboriginal or Torres Strait Islander, (79% in remote NT) compared with the second highest jurisdiction of Tasmania at 4.6%.[2] Over 40% of those within the aged care target population for services in the NT are Aboriginal compared to the national average of 3%.[3] Long-term health conditions affect 90% of Aboriginal and Torres Strait Islander people over the age of fifty-five[4]

Older people are entitled to an equitable standard of services that meets their needs, no matter where they live. As a fair and democratic society, we should ensure universal access to essential services for the frail and aged. A strategy based on 'competition and choice' in locations where there is no competition nor choice further disadvantages those who are already significantly disadvantaged. Investment in services needs to be refocused on needs rather than on markets.

The introduction of the National Disability Insurance Scheme (NDIS) has compounded the disadvantage faced by older people in the NT. There are very few service providers and little competition and choice, but there is a significant intersection between age and disability.

Big packages for aged and disability support services are heavily publicised but the reality is that the money is not being spent in the NT because there are no services. These funds are subsequently lost to the NT and re-allocated elsewhere.

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[1] Productivity Commission, *Report on Government Services 2019,* Chapter 14 Aged Care Services.
[2] ABS, *Census 2016*
[3] *Productivity Commission,* Report on Government Services 2019, Chapter 14 Aged Care Services.
[4] https://www.aihw.gov.au/reports/older-people/older-australia-at-a-glance/contents/diverse-groups-of-older-australians/aboriginal-and-torres-strait-islander-people

Key issues

- **The market is not an effective provider**

It preferences those living in profitable market segments and, in doing so, discriminates against those most in need.

- **Older people who need support should not be treated as consumers.**

Information about services and pricing is confusing and it is difficult for most people to adequately represent themselves in securing what they need at an appropriate price. Choice is illusory where there are thin markets and limited services. The competition model should not be applied to those most vulnerable seeking essential services.

- **Packages and funding levels are not translating into services.**

The headlines focus on the number and value of packages, but packages are meaningless if there are no services available. The take up of packages tends to become an inappropriate proxy for need, with investment withdrawn on the basis of a "use it or lose it" approach.

- **One size does not fit all**

While the 'competition and choice' model trumpets 'tailored solutions', in reality a standardised approach is applied, and people who don't fit the mould are left without support.

- **The introduction of the market-based NDIS exacerbates disadvantage in the NT.**

A high proportion of older Territorians also have disability issues. NT residents experienced a double disadvantage with the advent of the NDIS. Government and not-for-profit services are being wound down, leaving older people with nothing.

- **Quality regulation – poor service or no service.**

Quality regulation is important in thin markets because of the potential for monopoly providers to price gouge or lower standards. However, thin markets also suffer from high costs and difficulties in recruiting staff with skills and experience. In remote areas particularly, any service is better than none. Quality regulation needs to achieve a balance and promote and develop quality rather than setting unachievable goals or penalising providers.

- **Value and develop staff and carers**

Recruiting and retaining staff in the NT is difficult, particularly because in the aged care industry remuneration is low and the cost of living is high. Caring responsibilities in the NT are more likely to fall on friends and family.

- **Respect, value, protect**

Community awareness and engagement and cultural responsiveness are desperately needed to address the issue of elder abuse. And when older people are abused - usually by family members – victims, and other who report their concerns, need to know that these matters can be independently monitored and investigated.

- **Lack of available services outside urban areas leads to isolation and vulnerability**

The ‘postcode lottery’ when it comes to available services needs to be addressed. Lack of access to services compounds isolation and vulnerability, potentially exposing older people to abuse or neglect.

- **Capacity should be the default assumption**

Social and economic participation of older people is enhanced through a supported decision-making model. However paternalistic approaches through institutionalisation and the current guardianship model apply.

Recommendations

1. Provide a government-backed safety-net of services to ensure that older people have access to the same standard of services, regardless of where they live.
2. Commission demographic work and mapping of services alongside assessment of need to better plan provision of services and identify gaps.
3. Resource advocacy support to enable people's choice and control.
4. Invest in housing as the fundamental social determinant of wellbeing.
5. Ensure flexible design of service provision (vs packages), with the Commonwealth Government working in partnership with local organisations to ensure appropriate services are available and delivered.
6. Train, develop, support and adequately remunerate a local workforce providing aged care services.
7. Formally recognise the role and contribution that informal carers make and invest in upskilling and capacity building, particularly in remote communities.
8. Promote enduring connections to family and community and enable people to remain on country.
9. Maintain status and cultural connection and consider design of culturally appropriate, trauma informed services
10. Review impediments to ensuring that a person's will and preferences direct the decisions that affect their lives.
11. Provide safety in the provision of care and focus on improving quality while ensuring viability of services.
12. Fund the real costs of needs and services in a way that ensures availability and continuity of care.

Terms of Reference

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;

Many older people in the NT, would consider three meals a day and a roof of any kind over their head to be an absolute luxury. The focus on 'quality of facilities' assumes there are facilities, or even homes, for older people. For most of the NT this is simply not the case.

Needs and systemic failures

A needs-based system is fundamentally different from a consumer-based system. The focus of the current consumer-based aged care system is on those older people who are privileged enough to have access to services and the ability to exercise choice in purchasing them. This approach seems to be more about subsidising a private industry than providing an essential service. If aged care continues to be transactionally-based and focused on consumption, the 'postcode lottery' will continue to apply. People with negotiating power who live in the large, healthy markets in the cities of the south will continue to be favoured.

The concept of "choice and control" is illusory when those who are most vulnerable in our society are unable to, or incapable of, exercising choice and control. Where services simply don't exist, there is no choice. Competition may result in more choice and cheaper prices when it comes to buying toasters, but the wellbeing of vulnerable senior citizens should not be left to the vagaries of the marketplace.

Aged care, early childhood and now disability services provide for needs only to the extent that such activity is profitable. The addition of the NDIS to the list of privatised essential services has resulted in a further decline in the quality of life of older, vulnerable people in the NT.

The NT has less than half the number of residential places per capita of other states and territories.[5] The most recent aged care approvals round saw a take-up of only 50 places from 149 available. The 99 unallocated residential care places were re-allocated to New South Wales, Victoria and Tasmania. Although $60 million was allocated to capital works investment to establish, extend and refurbish new and existing homes in priority areas of rural and regional Australia, there were no grants allocated to the NT.[6]

At the very least, where there is no or little take up from private providers, unallocated resources should be invested where needs are highest, not where services are greatest.

[5] *Productivity Commission,* Report on Government Services 2019, Chapter 14 Aged Care Services.
[6] https://agedcare.health.gov.au/funding/aged-care-approvals-round-acar/2018-19-aged-care-approvals-round/distribution-and-targeting-resources-snapshot

Older Territorians with medical conditions are increasingly admitted as long-stay patients in public hospitals because of lack of appropriate residential accommodation. Currently, waiting times can exceed 200 days. This situation places additional pressure on a public health system that is already operating beyond capacity.

Chemical restraint and long wait for Residential Aged Care bed

A 75 year old Aboriginal client (X) diagnosed as bi-polar was placed on lithium to manage his condition. X was stable on the lithium mediation regime for years until he moved to a regional town and stopped taking/had difficulty accessing prescribed medications.

X subsequently became psychotic and was admitted to the Royal Darwin Hospital (RDH) diagnosed X with dementia.

X was advised he would need to reside in RDH for up to one year as there were no beds available in any of the four residential aged care facilities.

Generally older people in remote areas are not allocated home-care packages, because - while they may be assessed as having particular needs - the services are not available. Where home care packages are allocated, these often go unspent because the services are simply not available for purchase. The real costs are not reflected in the packages because a significant proportion of the package may be used to pay, for example, for travel or freight. The cost of accessing services in the NT also may require provision for interpreters and for carers/family to accompany the older person. Appropriate benchmarking, that takes into account the real cost of accessing services, needs to be applied to packages.

Where freight costs more than the equipment

Home care packages are at low levels due to the absence of services in the homelands of the NT and do not reflect the real costs of service provision in remote areas. A service at Yirrkala in East Arnhem Land reports being charged $1600 freight for two walkers, a wheelchair and a walking stick.

The packages do not cover essential items fundamental to the wellbeing of older people in the NT, particularly in remote communities where health and therapeutic services are largely unavailable. The use of home care packages to purchase food and household goods such as washing machines, fridges, mattresses and blankets would dramatically improve the environmental health and quality of life for those living in poor conditions in overcrowded households.

Older people with no access to essential personal items

Staff at an aged care provider in a regional town have raised concerns about many residents under public guardianship having difficulty accessing money through the Office of the Public Guardian to buy clothes, shoes and personal items. At one point, two residents were sharing one pair of dentures. Staff have used their own personal funds to pay for clothing and other personal items for clients.

Similarly, aged care service providers experience frustration because home care packages do not cover the purchase of essential items for wellbeing.

The services available are overwhelmingly urban-based and staff unskilled / underskilled in dealing with the complexity of the problems and the cultural diversity of the population. Older Indigenous patients from remote locations often find themselves bound to towns, unable to return home because of lack of services. Separation from family and country adds to generational trauma and further reduce their health and wellbeing.

The choice between home and support

A 70-year-old Aboriginal client living in Jabiru receives care Monday to Friday from a remote regional council including meals on wheels, social supports, transport and personal care enabling her to remain 'on-country'. Family/carers provide care for her on weekends. The client requires 24/7 supports for urinary incontinence and a multitude of health issues.

Staff found the client one Monday morning lying on her mattress covered in maggot infestation. On investigation it was found that the client had been left lying on the mattress all weekend with no change of continence pads. Food left with the client on the mattress became fly-blown and then infested.

The client was moved to Darwin, 300km away, and is now residing in a Residential Aged Care Facility against the wishes of family. However, the council had a duty of care to ensure the client received appropriate care, which could not be provided in the community or 'on-country' as no services were available.

Elder Abuse

While Elder Abuse is common in the NT, information about the extent of the problem is limited and there are few easy solutions. It is critically important to collect credible data on the incidence of elder abuse so that we can better understand the nature and prevalence of the problem. That said, the importance of people's stories must be captured. Like other forms of domestic and family violence, the reality of abuse is best communicated through lived experience.

A survey conducted by DCLS found that 72% of elder abuse victims were women, with 62% of Aboriginal and Torres Strait Islander background. In three-quarters of these cases, the abuser was a family member. Financial abuse was the most common form of abuse.[7]

Elder abuse takes on a different dimension in remote Aboriginal communities where resource sharing is traditional and effectively an obligation. Trauma, dysfunction and loss of connection to country have impacted on traditional practices to the detriment of older people. Support services are limited or non-existent and the community relies on its own members for support.

The usual recommendations for dealing with financial abuse include making a Will, completing an Advance Personal Plan, seeking legal advice, reporting scams, and monitoring bank accounts for unexplained expenditure. None of these are particularly relevant in a remote community setting.

National hotlines are also a popular response, but evaluations show they have little value to remote populations. On remote communities, access to phones is often limited and the person on the other end of the phone doesn't speak the community language, doesn't understand the cultural context, and usually has no idea of the caller's location. This causes delays and inappropriate referrals. The existence of these hot lines tends to raise expectations, but this is illusory when there are no services available.

Elder abuse offences require the cooperation of the victim to report issues to the police for investigation. However, because family members are so often the perpetrators, the victim may be reluctant to speak out. Many older people in communities see the solution as providing support for the perpetrator. Offering drug or alcohol rehabilitation, or help with housing and employment may remove the pre-conditions for the elder abuse. The solution is not always criminalising behaviour or seeking retribution.[8]

The family context is fundamental in Aboriginal society, and the reason that this type of abuse is rarely reported. It is why DCLS are advocating for a Safeguarding Agency in the NT.

The Final Report of the DCLS Elder Abuse Prevention Project contains a number of recommendations for consideration, which are at Attachment A.

[7] http://webcloud84.au.syrahost.com/~dclsorga/wp-content/uploads/2018/06/EAPP-Survey-Report-2018.pdf
[8] https://www.dcls.org.au/wp-content/uploads/2019/02/Elder-Abuse-Prevention-Project-Final-Report.pdf

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 with disabilities residing in aged care facilities

In general, aged care facilities are wholly inappropriate for younger people with a disability, because of the significant age disparity and the regimented nature of institutional settings like meal times, shower times etc. This often results in social isolation for the person with a disability. Potential issues such as declining health and increasing medical needs on the part of both the person with a disability and their carers, plus carer burnout, can result in inappropriate placements in aged care facilities.

However, models of service delivery in the NT often involve multi-disciplinary, one-stop shops, particularly in remote communities where few services are available. Any service is better than none, so specialisation may not be practical or viable.

Disability Service Delivery by an Aged Care Service

A young man with severe disabilities in a remote community has been allocated a significant package under NDIS. The only service available to him where he lives (NDIS will not include travel in plans) is the provision of breakfast three times a week by an aged care service provider. While this is clearly inadequate it is better than nothing and gives his sister, who looks after him, some respite.

Incidence of dementia

Aboriginal and Torres Strait Islanders experience dementia at rates three to five times higher than the general population.[9] The proposed Specialist Dementia Care Program is intended to offer 'specialised, transitional residential support"[10]. Given the lack of residential facilities (and housing) in remote areas it appears that people living on remote communities with dementia will again miss out.

[9] Radford K, Mack H., Draper B, Chalkley S., Daylight G., Cumming R, Bennett H, Delbaere K, Broe G., 11 (2015) *Prevalence of dementia in urban and regional Aboriginal Australians Alzheimer's & Dementia* (2015) 271-279 and Lo Giudice D , Smith K, Fenner S, Hyde Z, Atkinson D, Skeaf L, Malay R, Flicker L (2016) *Incidence and predictors of cognitive impairment and dementia in Aboriginal Australians: A follow-up study of 5 years* Alzheimer's & Dementia 12 252-261.

[10] https://agedcare.health.gov.au/programs/specialist-dementia-care-program

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;

The concept of 'home' in relation to 'people's desire to remain living at home as they age' is enormously variable. Home in a suburban environment may be very different to 'home' in remote Australia, where there is little or no access to appropriate services. Each version of 'home' should be supported. However, this is only possible where services exist.

In locations where competition and choice can't deliver, the Commonwealth Government must underpin universal access for disadvantaged Australians. Government must use its purchasing power and resources to ensure services are available and accessible, and to drive appropriate standards. The complexity of service delivery in the NT and the extent of disadvantage require more than mere per capita spending equity with other jurisdictions. The gap in the wellbeing, of Aboriginal Australians particularly, will not be closed if numbers are the only drivers.

Lack of remote aged care services

A health worker advised of an elderly Aboriginal man, a client of a remote health clinic, who was discharged from a regional hospital to an outstation/homeland. This man had bed sores and questionable cognition and would be returning to an outstation where he would be laying on a concrete floor with no mattress, no wheelchair and unreliable power and water resources. This man had recently been admitted to Alice Springs Hospital, having been given no food for three days.

The man's family wanted him returned to home. Staff at the health centre state they support dying on country, however the lack of suitable aged care services in remote communities leave older people open to inhumane conditions. These can cause extreme physical and medical conditions and leave them vulnerable to neglect and financial abuse.

One size does not fit all. Culture, intergenerational trauma, lack of basic housing and sanitation, and barriers to accessing services should be addressed by responsive services that reflect the diversity of needs. Place- based community-controlled solutions, such as Aboriginal Community Controlled Health Organisations, have been shown to deliver outcomes for those who are most disadvantaged through a model that delivers services face-to-face in their community, by people who speak their language and understand their culture and their circumstances.

A market-based system tends to exclude small local organisations that are best placed to deliver appropriate services, and to ignore the participation and contribution of community members and families. Co-operation and collaboration between services should be resourced to provide more efficient and effective service delivery where there is no competition.

Generic websites and phone lines exclude many people from access and don't have appropriate information about service providers and supports on the ground, or alternatively raise expectations that there will be services to refer to when this is not the case.

It will never be profitable to deliver services to small communities hundreds of kilometres from major service centres. That is not a good enough reason to abandon vulnerable older Australians

We reiterate the vision statement from the Aged Care Workforce Strategy remote accord:

"All elders deserve proper care and to live and die close to home with the care they need and deserve for a life well-lived, provided by a workforce they know and trust, which is well supported and trained, and accountable.

This will be a reality when governments, industry and community come together to develop flexibly approaches that work in many different communities but achieve the same outcome for families who live there."[11]

My Aged Care feedback (from consultations on the DCLS Elder Abuse Prevention Project)

"To make a complaint or a comment on the MyAgedCare portal, you need your Medicare number and My Aged Care Number. My clients don't carry that kind of information around with them!" - *Katherine Worker*

"Clients who are homeless, living in poverty and don't know how to use a computer are told – 'Go and log in on that computer'. They feel ashamed and helpless, so they just walk out." – *Darwin worker*

"The MyAgedCare website is inaccessible and unsuitable. If you have poor English skills, mild cognitive impairment, no internet access or don't understand technology, you have no hope. If you phone and don't have a landline, all the credit gets used on a pre-paid phone. And how do you complain? It's nearly impossible to work out from the website." – *Darwin consultation forum on Elder Abuse*

[11] Department of Health, *A Matter of Care Australia's Aged Care Workforce Strategy*, Aged Care Workforce Strategy Taskforce, June 2018

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;

Provision of services

The system should be strengthened by ensuring that services are available in the first place and that there is greater equity of access to these services. The current system is characterised by discrimination against those who live where there are thin markets and by a general failure to meet needs. In these circumstances, the Commonwealth Government must underpin services. Future allocations and investment should be based on need.

The Individual Subsidy Service model

The Consumer Directed Care model based on individual subsidies creates a significant administrative burden, diverting resources away from direct care. It threatens the sustainability of services in areas with small numbers of clients, or where clients are highly mobile. This impacts particularly on remote areas and communities where services are often provided by Not-for-Profit organisations and it is hard to recruit and retain staff. The uncertainty of funding for ongoing employment, infrastructure and equipment threatens the viability of the service. Block funding models, such as those used under the Aboriginal and Torres Strait Islander Flexible Aged Care Program, should be adopted as the standard funding model for remote communities.

Access to home care packages limited

An East Arnhem service provider is keen to transition to the Flexi-care model as the provider is required to foot the bill for individuals who are seeking home care packages until they have at least three referrals. ACAT will not do an assessment until this threshold is reached.

Quality

Prescriptive quality standards imposed without provision of resources to support transition, capacity building and compliance may result in marginal services folding. In profitable market segments, providers will be able to invest in improvements. But, where costs are high, economies of scale low, services and infrastructure poor, and skills and expertise limited, quality is likely to decline. Delivery of services in these areas is often abandoned by the market to the not-for-profit sector and government providers. Without additional financial support from government, these services must either rely on cross-subsidisation from more profitable sectors, or charge higher prices and thereby restrict access to services.

Immediate and sustained compliance with national quality standards by these services is not realistic under the current funding regime. Development plans that set realistic goals for improvement should be in place to assist organisations in areas where there is limited service delivery. These need to be accompanied by a block funding model and additional resources to build capacity.

The risk of imposing quality standards uniformly without appreciating the operational context is that service viability is threatened - so locations with limited services may end up with none. This has already happened in the early childhood sector, where quality standards imposed on childcare services in remote areas resulted in the closure of these services.

Monopolies are common in thin markets, where quality and price issues often go undetected. Providers avoid scrutiny because clients are reluctant to make complaints for fear of being left with no services at all.

Case study regarding Quality – Budget Based Funded (BBF) Early Childhood Services

The BBF Program funded approximately 244 early education services, mostly in regional, remote and Aboriginal and Torres Strait Islander communities. A block funding model was used in recognition of the fact that private providers were unlikely to establish appropriate services in these areas.

Funding for the Program subsequently ceased with the introduction of the Government's Jobs for Families Package. Services were required to transition to the new Child Care Subsidy (CCS) user-pays model – which provides direct subsidies to parents of children in private centres.

The Senate Committee on Education and Employment at Budget Estimates in 2018/19 heard that only 151 of the BBF services have received funding under the new Community Child Care Fund. The continuing viability of these services is threatened by imposition of higher quality standards, and a piecemeal payment in arrears funding model.

e. how to ensure that aged care services are person-centred, 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;

Tailored and Flexible Services

The onus should not be on the older person to inform themselves, identify appropriate services, and then seek to access them. Many of these people are not used to being asked what they want and often lack the expertise or capacity to determine what is appropriate. Often these decisions require high levels of medical and psycho-social expertise and depend on the availability of services and a consistency in their offerings. It should not be a case of "buyer beware".

Resourcing independent advocacy support is integral because many older people don't fully understand the complexities of the system. However, support for advocacy is very limited, particularly in areas where older people need it most. The benefits of advocacy can be seen in the NDIS roll-out, where participants receive 30% more in their packages when supported by an advocate. DCLS has seen older people being charged up to 55% of their Home Care Package for 'administration and case management'.

Flexible provision of services enables tailored service delivery and supports better outcomes in a way that choice and control will not. While lip service is paid to a rights-based framework the current model is more about shifting responsibility to the individual who may be ill-equipped to make choices.

Flexible service provision is better able to deal with the needs of cohorts of people who are extremely vulnerable. For example, the Stolen Generation in the NT, a small group of older people who have been through generational trauma. Stolen Generation members in the NT, unlike other states, have had no access to compensation, and only limited support. They are in desperate need of trauma-informed aged care services.

Guardianship

Older people in the NT are more likely to be subject to guardianship control by the state than any other jurisdiction. The NT has the highest incidence of guardianship per capita in Australia, with three quarters of those represented under public guardianship. Three-quarters of represented adults under the Public Guardian in turn identify as Aboriginal or Torres Strait Islander. Almost half of those under public guardianship are over 55.[12]

Respect for the independence and choice of those subject to guardianship orders (Represented Persons) varies significantly across Australia. Recent legal changes to the guardianship administration in the NT have had the effect of replacing supported decision-making with substitute decision-making, thereby reducing the human rights

[12] Northern Territory Office of the Public Guardian, *Annual Report 2017-2018*

of Represented Persons. Under the changes, Represented Persons are no longer entitled to separate legal representation, and a 'best interests' test seems to have subsumed consideration of the Represented Person's freedom of decision and action. A lack of services makes a paternalistic approach to looking after interests more likely.

Case Study – Putting the older person back in control

An elderly Aboriginal man under the guardianship of the Office of the Public Guardian (OPG) was being treated in a regional hospital. The man was dying, and the hospital could only provide limited services for him. There were no aged care facilities or services in his community, but the man wished to spend his remaining time back on country.

The OPG was concerned that the man would not be cared for appropriately on country. However, no onsite investigations were made within his community to properly assess the potential living conditions and carer support.

The decision was based on their perception of the man's best interests rather than his express wishes. The man's wishes, and views were not properly considered in determining what was in his 'best interests' and his wellbeing, as opposed to his health, seems not to have been considered at all.

The importance of informal carers

Informal carers are vital to supporting older people in the NT. However, because of the lack of services, the difficulties of negotiating carers allowances or other forms of support, and the assumption, particularly amongst Aboriginal communities, that there is a duty to support your elders, there is little formal recognition of this role. In fact, carers often incur penalties, such as the terminating of CDP payments because of their unavailability for work, despite the valuable role that they play. In other cases their vital role in supporting older people, such as in monitoring dialysis administered at home, is not considered active caring and not recognised for the purposes of a carer's payment.

One in four Aboriginal and Torres Strait Islander people aged 15 years and over provided care for a person with a disability, a long-term health condition, or old age. In the general population this figure is less than one in ten. The provision of care increases with remoteness (34% providing care).[13]

The role of community and family members in providing support where no services exist should be formally recognised with investment in capacity building and provision of resources, remuneration and respite.

[13] Australian Bureau of Statistics, *National Aboriginal and Torres Strait Islander Social Survey 2014-15*, and *Disability, Ageing and Carers, Australia: Summary of Findings, 2015*

f. how best 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;

While the question focuses on sustainability, part of the answer must lie in whether aged care services are currently meeting their objectives in supporting the health, wellbeing and ongoing participation of older people in society.

If aged care services are not designed to prioritise need then the existing two-tier system is likely to widen the gap, reduce productivity, and thus threaten sustainability. "Excessive inequality and entrenched disadvantage can erode social cohesion and hinder growth. It can also sap investment in education and skills and slow productivity growth."[14]

Increasing use of technology in the aged care system, such as integrated software in residential and community care, can improve delivery of care, reduce paperwork and increase efficiency. But this can only work where there is the infrastructure to support an IT system. In the NT, there are large areas without network coverage making such technology a non-viable proposition.

Capital Infrastructure / Housing

The NT rate of homelessness is approximately 15 times the national average with Aboriginal and Torres Strait Islanders representing a clear majority of this figure.[15] Addressing the issue of homelessness and adequate housing is fundamental to social and economic outcomes in the NT. This is outlined in the diagram below.

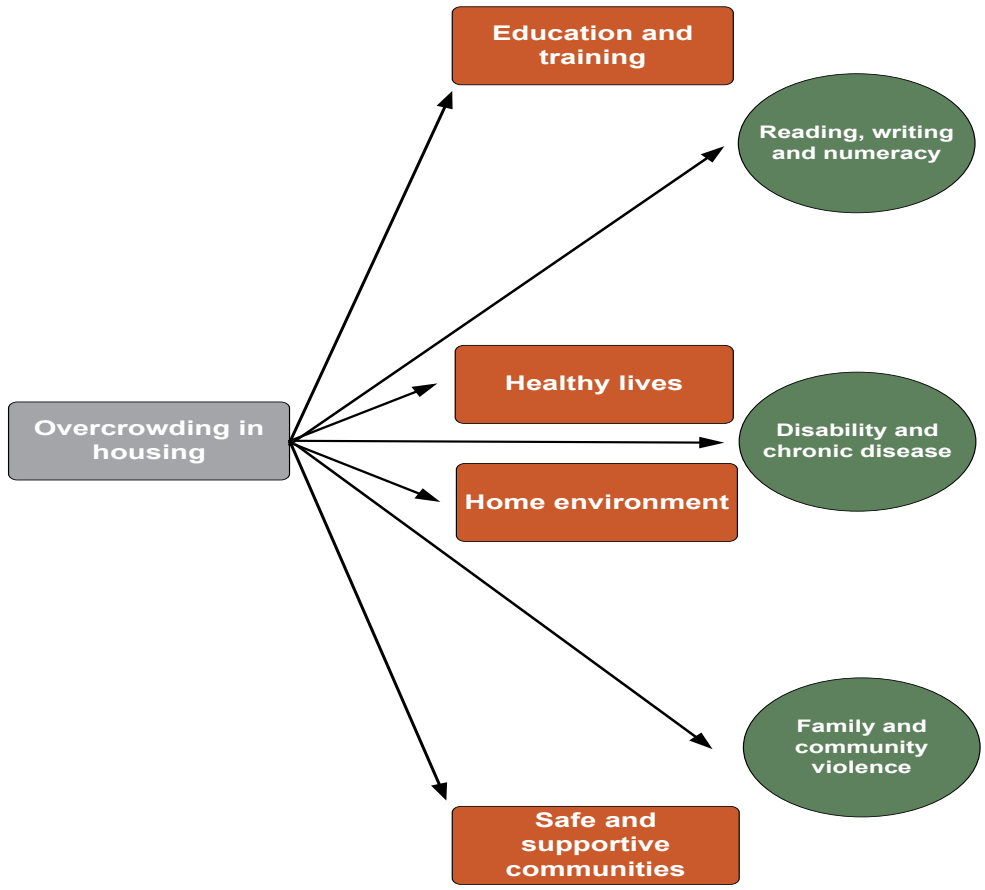
Housing is Key

"There's been no house built here in 30 years! Up to 17 people will live in one house. Overcrowding itself is abuse for old people – the get left with the bills! Even if they have a Territory Housing place they can't live there with no power, and they refuse to reconnect the 'til the Bill is paid. This impacts on health – oxygen connected, medicines kept cool. Prepaid meters aren't a thing anymore." – *Tennant Creek Community Member, Elder Abuse Prevention Project*

[14] Productivity Commission, *Rising Inequality, A Stocktake of the Evidence,* September 2018

[15] ABS, *Estimating Homelessness 2013.*

Housing as a foundation to wellbeing



Source: Figure 3.5.3 Multiple effects — overcrowding.

Aboriginal people want to die on country. Country is important to their identity and authority. The strength and the respected role of elders on country is an antidote to the scourge of elder abuse.[16] However elders are often prevented from returning to country because of the lack of services and overcrowded and sub-optimal housing. Investment in visitor accommodation or respite facilities, such as the Apwere Mwerre Visitor Park in Alice Springs, helps support return to country by facilitating regular visits to service centres. It also takes pressure off overcrowded town camps.

Institutionalised responses are not the answer in the NT, particularly given the experience of the Stolen Generation and those forced to live in missions. Culture, family, and connection to country need to be considered when designing service provision. Capital investment should therefore be focused on increasing community housing stock, particularly in remote locations, otherwise the impact of any care is necessarily limited. Private rental arrangements can sometimes be problematic as outlined in the case studies below.

[16] Productivity Commission, *Overcoming Indigenous Disadvantage, Key Indicators 2016.*

Private rental and ageing

Case study 1 - R is a 73-year-old man who lives by himself in a small unit. He has no family except for a daughter in Melbourne. R entered into a one-year tenancy agreement. R is computer illiterate. To pay his rent, he travelled to the bank in person to transfer money to the real estate agent. R began to have great difficulty getting around and asked whether he could pay his rent through weekly Centrelink payments. The real estate agent said he could not. R began to struggle to pay for medication, groceries and rent. As he had growing physical difficulty getting to the bank, he stopped paying rent and subsequently fell into rental arrears.

In addition, there is no washing machine in the unit. This is despite the fact R was promised a washing machine when he first signed his tenancy agreement. As R does not know how to use a mobile phone, he wrote letters to the real estate agent requesting that a washing machine be placed in the house. These letters were ignored. Unable to physically make it to a laundromat, R began to wash his clothes in the shower which was physically exerting and impacted his health.

R was evicted from his unit for rent arrears.

Case study 2 - F is a 67-year-old man who lived by himself in a small unit. He has no family except for a daughter who lives interstate. F had lived in the small unit for nearly two years. F has an array of medical conditions, including Parkinson's disease.

F was provided with some home care support by an organisation, which included cleaning, case management, and support for outside activities such as shopping and attending appointments. The organisation was often short-staffed and had difficulty providing regular services.

F fell into financial difficulties and missed numerous rental payments. He could afford the rent but the rental payments were scheduled to leave his account two days before his Age Pension was deposited into the account. Due to some memory issues he did not realise that his rent had not been taken out of his bank account. On a number of occasions, F withdrew the balance of funds from his account prior to the rent being debited from his account. F was subsequently evicted for falling behind in his rent.

F has had to go through a period of upheaval, relocating to temporary charitable accommodation, and will be required to move again once suitable longer-term lodgings are found. He has lost his bond and is now in debt.

F did not want to move into aged care accommodation because - despite his medical condition - he wants to live independently in the community as long as possible.

Value the aged care workforce

There are no standard national qualifications for people working in aged care facilities or under Commonwealth Home Support Program funding. According to Commonwealth Dept of Health statistics, in 2016, 70% of the aged care workforce (108,000 people) were Personal Care Attendants (variously called care workers/ support workers/ personal care assistants/ residential care assistants).[17] These are unregulated healthcare workers who support the delivery of care by assisting people with personal care and activities of daily living. In 2016, only two-thirds of aged care facilities reported that more than 75% of Personal Care Attendants have a basic Certificate III level qualification.[18]

The qualification most commonly held by these attendants is the Certificate III in Individual Support (previously Certificate III in Aged Care). Greater investment in training would enable current staff to upskill and new staff to gain this qualification. However, for people in rural and remote areas of the NT, such training is very difficult to access. Registered Training Organisations often don't service remote areas, so participants have to travel to regional centres at considerable cost. Funding training providers to travel to communities where there are services to provide block training for existing and potential staff, could go some way towards meeting this gap.

Retention of staff is also a significant issue in remote areas. The Commonwealth Dept. of Health 2016 statistics indicate that 72% of remote aged care facilities, and 87% of very remote aged care facilities, report staff skill shortages. This compares with 63% averaged across Australia. The most common reason given for this is the shortage of applicants with suitable skills, qualifications, experience and values. [19]

House share makes staffing possible

East Arnhem Regional Council (EARC) provide meals on wheels, medication support, group supports, and personal care for both HCP and NDIS clients. The Council currently has six staff and 47 clients. They are lucky to be able to extend these services as four of their staff live in the one house because there is no other accommodation available. They are forced to continually refuse requests for services, due to limitations on employing extra staff.

[17] Aust Govt Dept Health, The Aged Care Workforce, 2016. (2017), p.13

[18] Aust Govt Dept Health, The Aged Care Workforce, 2016. (2017), p. 10

[19] Aust Govt Dept Health, The Aged Care Workforce, 2016. (2017), p. 55

Conclusion

This submission illustrates that the aged care system discriminates against older people according to where they live. Older people are entitled to live their lives to the fullest, to live where they choose, to maintain their independence and be active members of their community. To support these rights they should, receive an equitable standard of services that meets their needs, no matter where they live. A credible and well evidenced assessment of these needs is required and services should be provided accordingly.

Older people deserve a choice of appropriate and affordable support and care services where and when they need them. For older people in the Northern Territory (NT), particularly Aboriginal and Torres Strait Islanders living in remote areas, the services simply do not exist. A strategy based on 'competition and choice' in locations where there is no competition or choice further disadvantages those who are already significantly disadvantaged.

Over-reliance on the market leads to gaps and inequities. Access to care in the NT is a problem. The number of people waiting for home care packages is far greater than the number of people receiving care at their approved level and the waiting times for home care packages are long. A safety net of government provided services is required to ensure that older members of society are not differentiated on the basis of the 'haves' and 'have nots'.

Supporting and adequately resourcing local approaches on a collaborative basis is fundamental to achieving outcomes and recognising the important role that community and family play in developing a positive culture for an ageing society.

Attachment A

Elder Abuse - Recommendations for further consideration
(From the DCLS Elder Abuse Prevention Project 2018)

Build the evidence base

- Promote greater understanding of the issue, and the development of appropriate policy responses, through the collection and collation of data and information, and through greater recognition of the context in which abuse occurs.
- Recognise the gendered nature of elder abuse by supporting policy and action to address gender inequality.
- Conduct research to better understand susceptibility and vulnerability to abuse: amongst women; Lesbian, Gay, Bisexual, Transgender, Intersex and Queer; Aboriginal and Torres Strait Islander; Culturally and Linguistically Diverse; remote; and homeless populations.
- Gather information on the motivation of perpetrators to guide preventative responses.

Change Community Attitudes

- Develop and resource programs in schools targeting young people focusing on respect for elders.
- Support community-led/place-based awareness activities that focus on promoting the value of older people.

Independent Monitors and Investigation

- *Establish an independent safeguarding agency to monitor and investigate allegations of elder abuse.*

Protect Money and Resources

- Create a single organisation that can receive reports from financial institutions about suspected financial abuse obtained in the course of conducting due diligence.
- Make legal information sessions about Wills, Advance Personal Plans and Powers of Attorney freely available to all older people, and resource a service specifically to assist people to complete Advance Personal Plans.
- Review legislation to clarify the responsibilities and limitations that apply to appointed attorneys, to ensure significant involvement of the person making the appointment.

Provide accessible and appropriate essential services

- Expand services that address cultural needs to support flexi-care models, clustered domestic residential care[20], and both day and long-term respite services.
- Establish a safety net to ensure all older people have access to services, particularly when the market is unable or unwilling to meet need.

Increase capacity and skills

- Resource skill acquisition, training and development and reward of aged care workers, and establish minimum staffing levels.
- Train workers to identify elder abuse, understand the factors that put older people and abusers at risk, and to implement strategies to protect older people from abuse.
- Provide support for people in remote communities to train and work in aged care and recognise the role of people in Aboriginal communities already providing care to older people.

Address barriers to access

- Support mobile and innovative services and promote community involvement, including training in technological engagement, to enable flexible information provision and service delivery.
- Increase appropriate housing stock to meet needs.
- Increase respite services which provide support to carers, and a place of safety and quiet for older people to socialise with peers, and link with health and other support services.
- Develop greater awareness and understanding of elder abuse to overcome impediments to reporting.

https://www.dcls.org.au/wp-content/uploads/2019/02/Elder-Abuse-Prevention-Project-Final-Report.pdf