



## **Northern Territory Office of the Public Guardian Submission to the Royal Commission into Aged Care Quality and Safety**

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**Younger people in residential aged care**

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## Introduction

The Northern Territory Office of the Public Guardian welcomes initiatives that encourage and support a better life for those with a significant and permanent disability who are living in residential aged care before the age of 65 years. The opportunity to provide a submission to the Royal Commission into Aged Care Quality and Safety is appreciated.

The Office of the Public Guardian is committed to providing adult guardianship services, information and advocacy that is responsive to the needs of the Northern Territory community and reflects contemporary, best practice guardianship principles within a human rights framework.

The Office of the Public Guardian was established under the *Guardianship of Adults Act 2016*, which also provides a legal decision-making framework for adults with impaired decision-making capacity in relation to their personal or financial matters. The definition of impaired decision-making capacity under the *Guardianship of Adults Act 2016* is broad and captures adults with a cognitive impairment from any cause including mental illness, dementia, intellectual disability or acquired brain injury.

The *Guardianship of Adults Act 2016*, also seeks to recognise the overall wellbeing, human rights and fundamental freedoms of persons with impaired decision-making capacity and align with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The UNCRPD's purpose is to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity". Article 5 of the UNCRPD directs equal recognition of all persons and prohibits discrimination on the basis of disability.

Compared to other jurisdictions, the Northern Territory has the lowest number of adults under guardianship orders; however, has the highest percentage of the population under guardianship. 75 per cent of people involved with the Office of the Public Guardian identifying as Aboriginal or Torres Strait Islander. A function of the Public Guardian is to advocate for adults with impaired decision-making capacity by promoting understanding and awareness of relevant issues. The Royal Commission into Aged Care Quality and Safety provides a unique opportunity to address systematic failures, which has led to poor quality of care for older Australians and young Australians living in aged care facilities.

This submission considers younger people in residential aged care, with a particular focus on the growing trend of Aboriginal and Torres Strait Islander people under the age of 65 being placed in aged care facilities as a result of a lack of flexible housing options and appropriate support services in the community.

The Office of the Public Guardian was encouraged and supported by Youngcare to make a submission on behalf of these younger people with a disability in residential aged care. We would like to acknowledge the assistance of Youngcare in this process.

The Office of the Public Guardian notes that the Royal Commission into Aged Care Quality and Safety has been provided additional material from the office, however due to the sensitive nature of the information this has been done in a closed format.



From left: Ms Aimee Bonfield, Youngcare Communications Officer; Ms Karina, Morris, Adult Guardianship Officer; Mr Shane Jamieson, Youngcare Connect Manager; Ms Sarah Krause, Youngcare Connect Coordinator; Ms Gabrielle Cleary, Team Manager Guardianship.

*Note: The case studies provided in this submission have been created from a series of life stories and does not represent an individual client.*

### **Younger people in residential aged care**

The Office of the Public Guardian has observed a disconnect between country and culture, with a high level of represented adults that identify as Aboriginal and Torres Strait Islander experiencing significant difficulties in receiving appropriate support services in remote communities. The limited provision of services in these communities often result with those needing aged care support, palliative care or a higher-level package being moved away from country to regional centres to access adequate services. Staff at the Office of the Public Guardian are often faced with a variation of 'Sophie's Choice', with neither options of hospital or aged care is viewed as the 'best', but as guardian's the decision as to where a represented adult will reside must be made with the alternative option at times being homelessness.

The circumstances that have driven the admission of younger Aboriginal or Torres Strait Islander people into residential aged care often stem from a lack of appropriate accommodation and support options available in regional and remote communities. The Office of the Public Guardian is aware of 16 represented adults in the Top End, and a further 14 represented adults in Central Australia that are under 65 years of age, identify as Aboriginal or Torres Strait Islander and currently living in aged care facilities. Of this cohort, the youngest represented adult is 44 years of age.

The majority of these represented adults wish to remain in their own home where they are connected to place, family and culture, with the supports that are necessary for as long as possible. However, the limited provision of services in remote and regional communities means those needing aged care support are required to move away from country to access services. While some services are Indigenous specific, a significant number of Aboriginal and Torres Strait Islander people live in mainstream facilities where culturally appropriate activities are not always available.

When these represented adults are moved to the nearest regional center, such as Darwin or Alice Springs to access adequate services, this inadvertently separates them from kinship ties, culture and country, which may adversely affect the person's health and well-being. Their experience of isolation often exacerbates behaviors of concern as they are not where they want to be. While relocating a person to a better-serviced regional centre aims to meet their physical needs, improvement in overall wellbeing is often compromised.

Represented Adult A was born with an intellectual disability and has a history of mental illness and substance misuse which has resulted in alcohol related brain damage. Guardianship orders came in place when the partner of Represented Adult A passed away.

Represented Adult A was living in a remote community and has indicated a desire to stay in the area, however, adequate supports services and accommodation could not be attained resulting in Represented Adult A moving to residential aged care.

Represented Adult A absconds regularly and their general health has continued to deteriorate since entering this care placement. With the full roll out of the National Disability Insurance Scheme (NDIS) the Office of the Public Guardian has been able to obtain access to the scheme for younger people in aged care facilities. Work has been undertaken to commence regular community visits through their NDIS plan as well as family visits to the residential aged care placement.

The Office of the Public Guardian has noted a growing fear of leaving communities to receive medical treatment because the preconception is "you go to hospital and you don't come home." This fear is further provoked by the duty of care the Office of the Public Guardian has in ensuring basic needs are being met, which at times results in represented adults not being able to return to their communities as there is no assurance they can receive the care they need.

The development, and uses when available, of a range of flexible housing options and support services would assist in addressing the lack of support and accommodation options experienced in regional and remote communities. We encourage early consultation during initial stages of planning when designing housing in these areas, as this would allow National Disability Insurance Scheme (NDIS) and aged care packages to take effect more efficiently. While the Office of the Public Guardian has explored options that involve modifying existing housing to assist represented adults returning to their home community, the lack of access to support services presents additional challenges in obtaining this goal. By way of example:

Represented Adult B sustained an acquired brain injury as a result of a motor vehicle incident. The injuries from this incident also led to an above knee amputation resulting in the permanent use of a wheelchair and the need for 24/7 support. Issues with violence and overcrowding in the home compounded the lack of appropriate accommodation and support services on community. Represented Adult B was moved to a nursing home.

Even though Represented Adult B expressed fears in leaving their home, the care and support provided in this placement have improved their quality of life. Represented Adult B has an NDIS Plan that includes funding for the modification of housing on community. Ongoing work is being undertaken to find appropriate accommodation and support services.

For many Aboriginal and Torres Strait Islander people in the Northern Territory, English is not their primary language and is seldom used. Therefore, when Aboriginal and Torres Strait Islander people relocate to regional centres, the language barrier may be insurmountable. The Office of the Public Guardian notes that the use of accredited interpreters for represented adults is infrequent and may compromise; effective communication, the ability to seek the views of the aged care resident, the ability to obtain informed consent to medication or treatment, the ability to design appropriate individual care plans and communication with family members. A particular need exists around effective communication to conduct culturally appropriate end of life discussions with family members, who frequently live a significant distance from the aged care resident.

Represented Adult C, has early onset dementia and a serious chronic heart condition that requires regular medication. Despite efforts by family members to provide care in the family home, the escalation of violent behaviours displayed by the Represented Adult made it unsafe for the care arrangement to continue.

Represented Adult C was initially admitted to hospital to stabilise health conditions and was provided access to additional health care services enabling a positive behaviour support plan to be developed and implemented.

Numerous options were explored to find appropriate housing and support services in the remote community while Represented Adult C remained in Hospital for an extended period although medically stable. Despite best efforts, the only accommodation capable of meeting the needs of Represented Adult C was an urban aged residential aged care.

The Office of the Public Guardian understands the complications encountered when finding appropriate placements that address the level of care required for this cohort of represented adults, however notes the importance of the encouragement and support that is required for the growth of appropriate support services and accommodation to avoid younger people with a disability living in aged care. It is important that the Royal Commission into Aged Care Quality and Safety recognises the diverse needs of younger people in aged care to ensure change occurs.