



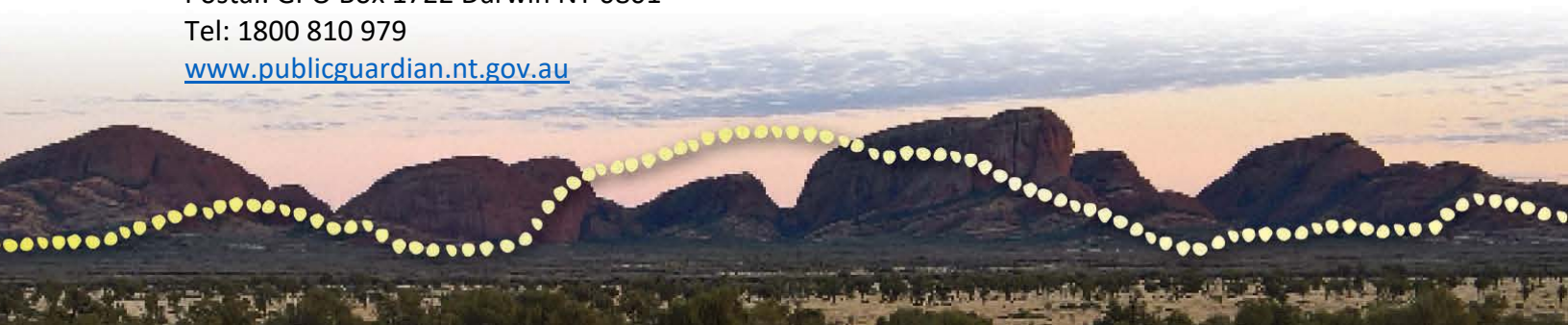
# **Northern Territory Office of the Public Guardian Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability**

## **HEALTH CARE FOR PEOPLE WITH COGNITIVE DISABILITY Issues Paper**

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**Office of the Public Guardian**  
Darwin Corporate Park  
Building 3, Level 1, 631 Stuart Highway, Berrimah  
Postal: GPO Box 1722 Darwin NT 0801  
Tel: 1800 810 979  
[www.publicguardian.nt.gov.au](http://www.publicguardian.nt.gov.au)



## **Introduction**

The Northern Territory Office of the Public Guardian welcomes the opportunity to provide a submission to the Health Care for People with Cognitive Disability Issues Paper released by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. Inquiries that consider the health needs of people with cognitive disability and necessary improvements, especially with regard to the unique Northern Territory situation, are strongly supported by the Office of the Public Guardian.

Established under the *Guardianship of Adults Act 2016* (the Act), 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 Act provides a legal decision-making framework for adults with impaired decision-making capacity in relation to their personal or financial matters. It includes a broad definition of impaired decision-making capacity that captures adults with a cognitive impairment from any cause including mental illness, dementia, intellectual disability or acquired brain injury.

The Act recognises the overall wellbeing, human rights and fundamental freedoms of persons with impaired decision-making capacity and aligns 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.

## **The Northern Territory context**

The Office of the Public Guardian teams are located in Darwin and Alice Springs and are responsible for providing guardianship services to approximately 570 adults represented by the Public Guardian. 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.

While most Territorians live in regional centres, a significant number live in remote and very remote areas. For Aboriginal people, who make up thirty percent of the Northern Territory population,<sup>1</sup> almost seventy seven percent live in remote or very remote areas<sup>2</sup>.

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<sup>1</sup> Department of Treasury and Finance (NT), Population - Northern Territory Economy: Aboriginal Population (2018) <<https://nteconomy.nt.gov.au/population>>.

<sup>2</sup> Department of Treasury and Finance (NT), Population - Northern Territory Economy: Background (2018) <<https://nteconomy.nt.gov.au/population>>.

The Northern Territory's situation is unique and poses challenges for service delivery to a small population spread across vast distances. The sparse population, harsh climate and rough terrain mean health and other supports and services in many parts of the Territory are limited. The Northern Territory's transient population impacts the retention of the skilled workforce as capable individuals have many alternate options elsewhere in Australia. The high cost of living in the Northern Territory is an additional challenge for those in the low socio-economic circumstances.

The Northern Territory population is comprised of many culturally and linguistically diverse groups. Approximately 78 per cent of people involved with the Office of the Public Guardian identify as Aboriginal<sup>3</sup>. Many speak English as a second or third language with a significant number living in remote communities. 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 experiencing significant difficulties in receiving appropriate support services, including health care, in remote communities.

The prevalence of disability in Aboriginal people and disparity in health is well documented. A few key facts include:

- In 2012-13 Indigenous Australians were twice as likely as non-Indigenous Australians to have severe or profound disability (based on age-standardised rates)<sup>4</sup>.
- The life expectancy for Aboriginal men is 63 years compared to 78 years for non-Aboriginal men.
- The life expectancy for Aboriginal women is 69 years compared to 83 years for non-Aboriginal women.
- The public hospital occupancy of Aboriginal Territorians is 70%.
- The homelessness population in the Northern Territory is comprised of 88% of Aboriginal Territorians.

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's inquiry into health care for people with cognitive disability provides an opportunity to consider and address systemic failures, which has led to violence, abuse, neglect and exploitation of people with cognitive disability in the health care environment.

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<sup>3</sup> The term Aboriginal is used throughout this document to refer to all people of Aboriginal and Torres Strait Islander descent who are living in the Northern Territory. The use of this term reflects the wishes of Aboriginal people in the Northern Territory. Department of the Attorney-General and Justice (2019). *Draft Northern Territory Aboriginal Justice Agreement 2019-2025*.

<sup>4</sup> Age-standardised disability prevalence, by Indigenous status, 2012-13 AIHW

### ***Barriers experienced by people with cognitive disability accessing health care***

The Office of the Public Guardian has observed a general deficit in understanding of cognitive disability issues in the health care sector. This results in similar barriers being experienced in the Northern Territory that are experienced nationally including:

- poor communication with the person with cognitive disability through lack of direct discussion with the person and the inadequate use of qualified interpreters and communication tools
- system issues including lengthy and inappropriate waiting times and
- a significant gap between policy and practice to meet the needs of people with cognitive disability.

This submission will explore aspects of these barriers in the context of the Northern Territory's unique circumstances.

It is the experience of the Office of the Public Guardian that the existence of these barriers negatively impact the quality of health care for people with cognitive disability in the Northern Territory. This results in unmet health needs and has a flow on effect of unmet social, emotional and cultural needs of the person.

Person centred and individualized support to meet the needs of the person with cognitive disability, and recognized as paramount in other facets of the person's life, including accommodation and disability services is often not reflected in health care services due to perceived and sometimes real deficits in the required resourcing of this support. In actuality short term, concentrated resourcing to provide a person centred, individualized response at the outset of the person's interaction with the health care service to meet the needs of the person will lead to increased health outcomes and therefore decreased resourcing in the long term.

In the Northern Territory, the limited provision of health services in remote and regional communities means many Aboriginal people needing ongoing, specialised or complex health care are required to move away from their home community or country to access services. The move to the nearest regional centre, such as Darwin or Alice Springs to access adequate health services inadvertently separates individuals from kinship ties, culture and country and adversely affects the person's health and well-being. While relocating a person to a better-serviced regional centre aims to meet their physical needs, improvement in overall wellbeing is often compromised. This experience is not limited to those that identify as Aboriginal but extends to all Territorians living outside Darwin or Alice Springs where access to health services is limited.

Conversely the delivery of health services to remote areas of the Northern Territory presents significant challenges not faced in regional centres either in the Northern Territory or across Australia. The impact of climate, distance and lack of infrastructure combined with the sparsity of population creates financial hurdles which necessitate creative methodology to maximise service options, especially in health care. On many occasions creative methodology will still fall short of the physical and emotional needs of Aboriginal peoples living in remote communities.

For many Aboriginal people in the Northern Territory, English is not their primary language and is seldom used. Therefore, when Aboriginal people relocate to regional centres, the language barrier may be challenging. 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 person, the ability to obtain informed consent to medication or treatment, the ability to design appropriate individual care plans and communication with family members. Health services specifically designed to address the cultural needs of Aboriginal people are often under resourced to meet the demand for service.

In regional centres the Northern Territory's transient population creates barriers for people with cognitive disability accessing health care from a regular and consistent general practitioner. There is a high turn over of general practitioners in regional centres and those who are permanent or long term Territory practitioners have limited capacity to accept new patients or are unavailable for an appointment at short notice. For people with cognitive disability and their family or carers this results in a lack of continuity of care, frustration at having to continually explain their health and care needs and a reluctance to seek health care unless absolutely necessary.

The Office of the Public Guardian has experienced a person's discharge from hospital to a nursing home being reliant upon the person being under the care of a general practitioner. The limited number of general practitioners practicing in the person's regional centre who had capacity to accept new patients meant that the person's discharge from hospital was delayed.

Due to the limited number of specialists residing in the Northern Territory and many specialists providing only a visiting service, accessing specialist services in the Northern Territory is difficult and often accompanied by long waiting periods or dependent upon a person's financial capacity to fund the specialist cost or to fund private health care. The effects of delayed diagnosis and treatment of a health condition for a person with cognitive disability is often exacerbated and results in deterioration of other aspects of the person's social and emotional wellbeing.

Hospitals present additional and significant barriers to people with cognitive disability accessing health care in the acute care settings. The pressure on acute care settings is well documented and there is commonly a one size fits all approach. Inadequate resourcing of these services generally, coupled with system changes needed to accommodate the individualized needs of people with cognitive disability means there is a tension for health services between meeting the needs of the majority, who fit within mainstream services or meeting the needs of people with cognitive disability and thereby inadvertently increasing the unmet need of the majority and placing further pressure on the health service.

### ***The NDIS and accessing health care***

The Office of the Public Guardian has observed difficulties for people with cognitive disability in the interface between the NDIS and accessing health care. It is often difficult to attribute if a person's needs arise from a health condition or from their disability which has seen a person's disability needs not being met under the NDIS and similarly not met under the health system due to cost preclusions or unavailability of the health care service.

The Office of the Public Guardian has witnessed an alternative medical procedure to address a diagnosed medical condition not being offered to a person with cognitive disability, due to cost, even though it was determined that the traditional medical procedure was unsuitable for the person due to their cognitive disability.

There is a disconnect between supports provided under the NDIS and health care provided to people with disability. This disconnect is created by a lack of co-ordination and information sharing between the two systems and an inability of the person's NDIS supports to go with them when they are accessing health care, particularly in hospitals.

For some people their cognitive disability may only become apparent during the course of accessing health care. While the person's support needs are being assessed and funded under the NDIS the person is required to navigate the health system unsupported. This may be particularly challenging if the person is required to travel to a regional centre or interstate to receive the required health care.

### ***Health care for diversity***

The Office of the Public Guardian advocates for health care that is equitable and recognizes and provides for the needs of all people with disability. Health care for people with disability should be person-centred and individualized and should take into account the specific support, communication, emotional and cultural needs of the person.

Across many health services there is a gap between policy and practice in the provision of services to accommodate the needs of people with cognitive disability. Often private and public health services will have the required policy to meet service standards but have not embedded this policy into practice through system changes, resourcing or continual education of new and existing personnel.

Access to mainstream services has been a significant focus of disability advocacy in past years. Access demands that these services must still accommodate the individual needs of people with cognitive disability and where necessary provide specialized services to ensure this occurs. This may include specialist disability clinics and outpatient clinics that can accommodate the needs of people with cognitive disability, including reduced or nil waiting times, low stimulus waiting rooms, longer consultation times without increased cost and health care professionals experienced in working with people with cognitive disability.

Focused and continual education and awareness of disability issues must occur in tertiary institutions and through vocational training. This education and awareness must address not only the theory and policy around the rights of all persons with cognitive disability in accessing health care but the practical steps as to how this may occur in practice.

Hospitals and acute care settings, where there is the greatest risk of disconnect from the person's support networks, including family and carers, specifically modified assistive technology and routine, should be flexible in their response to people with cognitive disability. On hospital wards this may include more single patient rooms, the ability to accommodate the person's support

person in the room or ward, low stimulus environments and the use of interpreters or other communication tools to communicate with the person.

For people with cognitive disability with complex needs a multi-agency approach will often be necessary to ensure a collaborative approach to addressing the health and other needs of the person simultaneously. This may include emotional and wellbeing needs, cultural needs and the provision of appropriately supported accommodation.

### ***NDIS and health systems working better for people with cognitive disability***

Clear policy must be developed and enacted to ensure that information relevant to a NDIS funded person with cognitive disability can be shared with health services and that where necessary NDIS funded service providers can assist the health service in meeting the needs of the person with cognitive disability. For example, this may include a positive behavior support practitioner working with hospital staff to modify an approved positive behavior support plan that can be implemented in the hospital setting while the person is receiving treatment.

NDIS funding should extend to support workers familiar with the person with cognitive disability continuing to support them in the hospital environment. The support workers are likely to already have a good understanding of the person and their needs and how these can be met to optimize the health outcomes of the person.

It is paramount that increased coordination occur between NDIS and health services to achieve greater health outcomes for people with cognitive disability. Professionals working in both areas should be cognizant of each other's needs and develop clear lines of communication. Education between the two sectors would help to ensure an understanding of the role and importance of each in the person with cognitive disability's life.

Stable, supported accommodation is a key factor in improved health outcomes for people with cognitive disability. The Northern Territory government together with service providers must continue to address the thin market of service providers specializing in supporting people with complex needs in the Northern Territory. Appropriate housing stock must also be secured to offer choice and flexibility in accommodation.

For remote and very remote communities incentives and supports must be offered to service providers to develop supported accommodation models to support Aboriginal people with cognitive disability to live on country while still having their health and support needs met.

### ***Causes of violence, abuse, neglect or exploitation in health care***

It is the experience of the Office of the Public Guardian that people with cognitive disability experience violence, abuse, neglect or exploitation in health care because as a system the health care system is not equipped to respond to the individualized health, support, emotional and cultural needs of the person.

In the Northern Territory this is commonly witnessed in health services by the use of restrictive practices. Similarly to many people, a person with cognitive disability will display frustration when they have unmet health, support, emotional or cultural needs and for a person with cognitive

disability this can often be expressed with behaviors that may pose risk to the safety of the person or others. In health services and particularly hospitals, the inability of the health service to provide an individualized response to these needs and consequent behaviours results in the use of restrictive practices, most commonly chemical, physical and environmental restraints to manage or modify the person's behavior and administer the required health care. While this may address the person's health needs it does not address the underlying reason for the behaviour and consequently the behaviour often continues, creating a cycle of behaviour and subsequent use of restrictive practices.

There is currently no legislation in the Northern Territory to regulate and monitor the use of restrictive practices in health care services. Guardians are considered by some as appropriate persons to authorize the use of restrictive practices for persons under guardianship. It is the view of the Office of the Public Guardian that the significant interference with a person's human rights through the use of restrictive practices (unless clearly for health purposes) demands a robust and transparent authorization process by a specialized independent authority.

For culturally and linguistically diverse people with cognitive disability the risk of experiencing violence, abuse, neglect or exploitation when receiving health care is compounded if the health service is unable to effectively communicate with the person and their family or carers and/or have an appreciation of the cultural needs of the person.

The specific barriers to accessing health care in the Northern Territory contribute to the neglect of Aboriginal people in health care because the provision of health services in remote and very remote locations is minimal or insufficient.

Health outcomes for people with cognitive disability are often dependent upon their support network, including family and carers and their level of advocacy for the person. Although unfounded, it is for this reason that the Office of the Public Guardian is often seen as the preferred guardian in an attempt by family and carers to secure better outcomes for the person. This dependence on support networks for health outcomes can be linked to instances of violence, abuse, neglect or exploitation of people with cognitive disability who do not have an adequate support network to advocate on their behalf.

***Measures to prevent persons with cognitive disability from experiencing violence, abuse, neglect or exploitation in health care***

System changes are required across all health care systems including in the areas of education, disability awareness, disability inclusion plans and improvements in quality standards. There must be an acknowledgement of the need to provide individualized, person centred support for people with cognitive disability while addressing their health needs. It is the experience of the Office of the Public Guardian that this individualized, person centred support will lead to greater health outcomes for people with cognitive disability.

System supports are particularly necessary when a person with cognitive disability does not have the necessary informal or other supports, including family and carers to advocate for them and ensure their needs are met.



Health services should be appropriately resourced to spend time with people with cognitive disability to build relationships of trust and to develop and understand the person's required level of communication needs. For Aboriginal people this is likely to include the use of accredited interpreters and cultural brokers.

People with cognitive disability and their family and carers should feel confident that if they complain about violence, abuse, neglect or exploitation in health systems the person's health care will not be compromised by the withdrawal of service or care by the health service. This is particularly important across the whole of the Northern Territory where there is a thin market of health services. It is magnified in relation to specialist health services where there may be only one specialist in the field who works in the Northern Territory and in remote and very remote communities where there may be only one health service.

It is not always obvious for a person with cognitive disability or their family and carers to identify that the person has been subject to violence, abuse, neglect or exploitation in health care. Barriers that exist to reporting the abuse include disability barriers – communication, sight, hearing, literacy skills, understanding how and who to make a complaint to. In a litigious environment health services can be reluctant to promote the complaints process.