

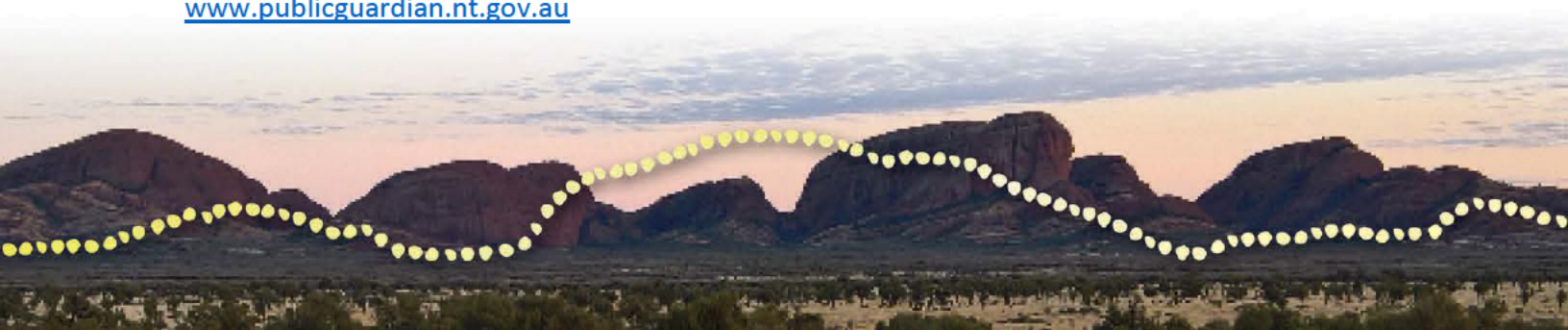


Northern Territory Office of the Public Guardian Submission to the Senate Select Committee on Autism

April 2020

Office of the Public Guardian
Darwin Corporate Park
Building 3, Level 1, 631 Stuart Highway, Berrimah
Postal: GPO Box 1722 Darwin NT 0801

www.publicguardian.nt.gov.au



The Northern Territory Office of the Public Guardian welcomes initiatives that encourage and support a better life for adults with a disability, including autism and appreciates the opportunity to provide a submission to the Senate Select Committee on Autism.

Established under the *Guardianship of Adults Act 2016*, 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 *Guardianship of Adults Act 2016* 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 Aboriginal¹ people, who make up thirty percent of the Northern Territory population,² almost seventy seven percent live in remote or very remote areas³.

¹ 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*.

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

³ 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 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. 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 from 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.

A function of the Public Guardian is to advocate for adults with impaired decision-making capacity by promoting understanding and awareness of relevant issues. This submission to the Senate Select Committee on Autism provides an opportunity to share experiences of people with autism involved with the Office of the Public Guardian and advocate for coordinated strategies to improve the health, education and employment outcomes for this group. The Office of the Public Guardian strongly advocates for the development and implementation of a National Autism Strategy to provide strategic and coordinated support to Australians with autism with diagnosis, education, employment, mental health and social inclusion.

Statistics of represented adults with autism

There are currently 980 adults subject to a guardianship order in the Northern Territory. The records of the Office of the Public Guardian indicate that 73* of these adults have autism as a primary or secondary diagnosis. Of these 73:

- 17 are female and 56 are male
- 33 identify as Aboriginal or Torres Strait Islander

*This figure is not warranted to be 100 percent accurate however does provide some indicative data regarding adults under guardianship in the Northern Territory.

Current approaches and barriers to consistent, timely and best practice autism diagnosis

The *Guardianship of Adults Act 2016* provides a legal decision-making framework for people with impaired decision-making capacity over the age of 18 years. On most occasions when a person becomes subject to a guardianship order and known to the Office of the Public Guardian they have already been diagnosed with any relevant disability, including any diagnosis of autism. Therefore the Office of the Public Guardian's direct experience is in relation to adults over the age of 18 years post autism diagnosis.

As an advocate for adults with impaired decision-making capacity the Office of the Public Guardian is aware of current approaches to consistent, timely and best practice diagnosis and how these impact the available interventions and the effect of these interventions to the person's quality of life across their whole life, including when they are subject to a guardianship order. It is the view of the Office of the Public Guardian that there appears to be a general emphasis on diagnosis instead of early intervention pre-diagnosis for children failing to meet developmental milestones. The Office of the Public Guardian advocates for a strategic and equitable intervention plan that targets concerns such as language development and sensory issues and encompasses all children across the autism spectrum from low to high functioning, rather than an emphasis on diagnosis that targets moderate to severe levels of disability. This early intervention would minimise future reliance on interventions such as adult guardianship in adulthood.

It is widely documented and accepted that the earlier there is intervention for a person with autism, with tailored supports and education, the better the outcomes. This is especially true for high functioning persons with autism who may gain employment with the right supports. The Office of the Public Guardian advocates for a holistic, autism specific, multidisciplinary approach to assessment and intervention to optimise developmental opportunities for all persons with autism. The specific challenges in the Northern Territory of sparse and geographically dispersed population, limited infrastructure and services in remote and very remote communities and limited professionals with autism expertise must be addressed to ensure this approach is available and accessible to all Territorians.

The demand for and adequacy of Commonwealth, state and local government services to meet the needs of people with autism at all life stages

It is the experience of the Office of the Public Guardian that there is high, unmet demand for Commonwealth, state and local government services to meet the needs of people with autism at all life stages. Improvements have been evidenced since the introduction of the NDIS however there is still significant demand and necessary growth and development of expertise in services. In particular in relation to the areas of social skills groups, skills development, community networking, friendship development, support for families and carers and employment services tailored to people with autism.

For persons under guardianship inadequate intervention and support services experienced by people with autism is evidenced in their need as adults for continued and extensive support and development in areas that were not addressed in earlier years. This has led to reduced opportunities for independent living and employment opportunities.

The interaction between services provided by the Commonwealth, state and local governments, including: health and mental health, education, employment, justice and housing

There is currently a disconnect between services provided by different levels of government and across service sectors. Overall, none of the service sectors provide either a comprehensive service to address the needs of people with autism or provide a seamless transition between service

sectors. It appears difficult for service sectors to accommodate the range of complex needs that exist across the autism spectrum and the Office of the Public Guardian advocates for a co-ordinated, strategic and holistic approach for all service sectors.

For adults with autism there is often a misdiagnosis of a mental health condition for example anxiety or depression instead of a diagnosis of autism resulting in inappropriate supports and/or medication. On other occasions it is difficult to obtain a diagnosis from either health or mental health and individuals get stuck between these service sectors with no diagnosis and therefore limited or no support or intervention, including under the NDIS. This is exacerbated if there is a dual diagnosis of autism with a mental health condition for example, anxiety or depression. In the Northern Territory there is no specific service that specialises in the diagnosis, treatment and monitoring of people with autism and mainstream health services are not experienced in providing health care while meeting the sensory and/or behavioural presentations of people with autism. This results in significant barriers to accessing health and mental health care and leads to reduced health outcomes and quality of life.

The Office of the Public Guardian experience is that the education system is underfunded and inexperienced to meet the needs of children with developmental delays and sensory needs and who may or may not be within the autism spectrum. The effect of this is evidenced in adults with reduced educational outcomes and therefore reduced independent living, higher education and employment opportunities.

Supports necessary to assist people with autism to participate in the workforce are not adequate and this has led to reduced outcomes in employment and quality of life and lost opportunity of valuable and necessary contribution to society. People with autism have many strengths, expertise and skills to offer the workforce, which demand all levels of government and service sectors to co-ordinate and strategize to identify opportunities in the workforce and incentivize public and private organisations to harness the benefits of increasing the participation of people with autism in the workforce. Failure to harness this opportunity leads to unnecessary reliance on government funded services and benefits.

System failures of inadequate intervention and support and a lack of understanding of the sensory and behavioural presentations of people with autism often results in their involvement with the criminal justice system. The coordination between service sectors including justice, health and mental health is necessary to support people with autism who are or may become involved in the criminal justice system in any capacity, including as an alleged offender, victim or witness. There must be an increased understanding of the needs of people with autism and how the criminal justice system can respond to address these needs.

Appropriate and available accommodation continues to provide significant challenges to people with autism in the Northern Territory. There is currently insufficient stock to offer real choice and control to people with autism and there is a disconnect between service sectors including health,

human services and housing to source appropriate housing and support within reasonable periods of time.

The social and economic cost of failing to provide adequate and appropriate services, including to support key life stage transitions of people with autism

The social and economic cost of failing to provide adequate and appropriate services, including to support key life stage transitions of people with autism, to the individual, their family and carers and the community as a whole, is significant. There is incredible potential for people with autism to contribute to the workforce and their community and it is imperative that governments and businesses harness this potential through whole of life support and services. Strengths of appropriately supported people with autism include reliability, lateral thinking, non-standard problem solving, focussed attention to tasks and adherence to routines and procedures.

The failure to provide adequate and appropriate support services to people with autism pre and post diagnosis also includes the increased need in intensity and duration of supports and reduced health, education and social outcomes.

The adequacy and efficacy of the National Disability Insurance Scheme (NDIS) for people with autism

The ability of NDIS planners to understand and address the complex needs of participants, including the complex needs of people with autism across the autism spectrum, is dependent on the individual planner. Overall, planners are not always able to understand the complexities of a participant's disability and therefore the required level of supports is not incorporated in the participant's plan.

The growth of the human services support industry in the Northern Territory is dependant upon NDIS planners having an understanding of both the supports that are currently available as well as what supports could be provided to the participant. This is particularly relevant to NDIS plans for people with autism where the growth of specialist and holistic services is essential to meet the needs of this group. There is also a necessity to debunk the belief among NDIS planners that if supports or services are not available in the Northern Territory then the relevant funding should be removed from plans. This is not in line with participants' needs nor does it encourage or stimulate market growth.

The Office of the Public Guardian notes that the Complex Support Needs Pathway (the complex pathway) has positively impacted the outcomes for participants with complex needs. This includes participants with autism, participants with other complex needs and participants transitioning from prison who are often interacting with multiple service systems including justice, health, mental health and disability. In 2018-19, 24 adults under the guardianship of the Public Guardian in the Northern Territory were involved with the criminal justice system. Of these 24 represented adults, 6 were prisoners and 18 were subject to Part IIA of the *Criminal Code Act 1983* (where alleged offenders with a cognitive impairment are deemed not guilty or unfit to stand trial). As at 30 June 2019, 4 represented adults remain in prison and 15 of the represented adults who are subject to

Part IIA of the *Criminal Code Act 1983* are supported in the community. This decrease in numbers may be attributed to the strong advocacy of the Office of the Public Guardian for appropriate supports to be offered through both the NDIS and Northern Territory Government. This involvement has also highlighted the need for further growth in this area including a systems approach that is not reliant upon individual advocates and service personnel and an increased interaction between the criminal justice system and the NDIS to ensure a smooth transition from the criminal justice system to community supports.

Participation of people with autism in the NDIS planning process

It is the view of the Office of the Public Guardian that the adequacy and appropriateness of supports to empower many participants, including people with autism to participate in the NDIS planning process and exercise self-determination through choice and control over their support services requires significant improvement to achieve consistently positive outcomes. The involvement of participants is crucial in empowering the participant and ensuring their rights and needs are acknowledged and incorporated into the NDIS plan. While the Office of the Public Guardian has noted an increase in the use of interpreters for participants that speak English as a second language, cultural considerations during the planning process can still be improved.

Unfortunately, the planning process does not always draw optimal outcomes because of the general nature and structure of the meetings. In addition to this, the assessment tools that are used are not meaningful in all situations but particularly for people with autism, nor is the process coming from a strengths approach. Instead, participants are asked to justify their deficits to enable funding to be allocated, which is very difficult for participants, family and carers and support providers. Inappropriately worded questions can exacerbate the existing discomfort of a participant who is not comfortable talking to a stranger about personal matters leading to critical information not being disclosed and basic supports not being included in plans. There is a specific skill set required by planners to maximise the involvement of people with autism in planning meetings.

If the NDIS planning process is not undertaken adequately by skilled and experienced planners then the resulting plans and outcomes for participants is sub optimal. This then results in the need for reviews of plans that are often not conducted in a timely manner and require huge amounts of additional resources. The importance of the planning process needs to be recognised given the success of the scheme hinges on this process which should also be simplified to maximise participant participation.

The development of a National Autism Strategy and its interaction with the next phase of the National Disability Strategy

The Office of the Public Guardian strongly supports the development of a National Autism Strategy. In 2018 the Australian Bureau of Statistics reported there were 205,200 Australians

with autism, a 25.1% increase from the 164,000 with the condition in 2015⁴. This increase in the prevalence of autism in Australia demands a national strategy to ensure a coordinated national approach to support people with autism to maximise their experiences and potential and participate as equal citizens across all facets of their life, including health, education and employment.

This strategy should complement the continued national approach to supporting people with disability through the next phase of the National Disability Strategy.

The adequacy of funding for research into autism

It is the view of the Office of the Public Guardian that the increase in prevalence of autism in Australians demands increased funding for research into autism to identify causes of this increase and to inform intervention strategies. It is widely accepted that with appropriate and adequate early intervention and supports the health, educational and employment outcomes for people with autism are significantly increased. This warrants increased funding for research to ensure the best practice diagnosis, intervention and support for people with autism across Australia.

The social inclusion and participation of people with autism within the economy and community

There must be an increased focus on the social inclusion and participation of people with autism within the economy and community to identify educational and employment opportunities for people with autism and map these opportunities to individuals. The NDIS provides a significant opportunity for this to occur across the human services industry and beyond.

People with autism have many skills and strengths which should be engaged to provide productive and meaningful contribution to communities and the Australian economy. Incentives must be offered to public and private organisations to engage with and support people with autism in the workforce. There should be coordinated strategies to promote these incentives and engage with employers, through targeted education and awareness about autism and how people with autism may be involved in the workforce.

It is the experience of the Office of the Public Guardian that there is inadequate community understanding about adults with autism and how they may be engaged and supported within the community. This also requires coordinated strategies to raise awareness about autism and promote the strengths and abilities of people with autism across society.

The capacity and sustainability of advocacy, self-advocacy and self-determination supports for people with autism, including mechanisms to self-represent to government as enshrined in the United Nations Convention on the Rights of Persons with Disabilities

Frameworks for supporting people with autism to self-advocate and maintain freedom of decision-making including self-determination and self-representation must be strengthened. Current

⁴ ABS Survey of Disability, Ageing and Carers: Summary of Findings 2018

guardianship and substitute decision-making frameworks must be reviewed to ensure there are legislative frameworks to support and promote supported decision-making to safeguard the right to autonomy of decisions and actions. The risk for people with autism to be considered as having impaired decision-making capacity is heightened by their sensory and/or behavioural presentations. This is despite a consensus that with the right supports such sensory and/or behavioural presentations can be managed and the person with autism supported to make decisions and self-advocate. NDIS funding and service development need to be harmonised to promote an appropriate service response to these important areas.

Any other related matters

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,⁵ almost seventy seven percent live in remote or very remote areas⁶. The prevalence of disability in Aboriginal people is high and well documented. In 2012-13 Indigenous Australians were twice as likely as non-Indigenous Australians to have severe or profound disability (based on age-standardised rates)⁷. It is foreseeable that the prevalence of autism among Aboriginal people would be similar to the prevalence of disability. This prevalence necessarily also equates to a high demand for NDIS supports by Aboriginal people.

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 or supports are required to move away from their home community or country to access this care and support. The move to the nearest regional centre, such as Darwin or Alice Springs to access support 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 and supports is limited.

These specific considerations for Aboriginal people with autism living in the Northern Territory must be recognised and addressed in any National Autism Strategy. The Office of the Public Guardian advocates for targeted consultation to occur with representative Aboriginal groups and communities.

⁵ Department of Treasury and Finance (NT), Population - Northern Territory Economy: Aboriginal Population (2018) <<https://nteconomy.nt.gov.au/population>>.

⁶ Department of Treasury and Finance (NT), Population - Northern Territory Economy: Background (2018) <<https://nteconomy.nt.gov.au/population>>.

⁷ Age-standardised disability prevalence, by Indigenous status, 2012-13 AIHW