

# Tasmanian Government Submission

SELECT COMMITTEE ON AUTISM

April 2020

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## I INTRODUCTION

The Tasmanian Government welcomes the opportunity to provide a submission to the Select Committee's Inquiry on Autism, looking at the services, supports and life outcomes for people living with autism in Australia, and the associated need for a National Autism Strategy.

In its *Disability, Ageing and Carers, Australia: Summary of Findings*<sup>1</sup> the Australian Bureau of Statistics (ABS) reports that in 2018, there were 205,200 Australians with autism, a 25 per cent increase since 2015. Further, the latest published Quarterly Report to the Council of Australian Governments (COAG) Disability Reform Council<sup>2</sup> shows Autism Spectrum Disorder (ASD) to be the largest primary disability category within the National Disability Insurance Scheme (NDIS). In Tasmania, there were 2,190 participants with a primary disability of autism as at 31 December 2019. This represents 32 per cent of all NDIS participants in Tasmania, which is consistent with a national figure of 31 per cent.

The Tasmanian Government's *Accessible Island: Tasmania's Disability Framework for Action 2018 – 2021* articulates a vision for a fully inclusive society that values and respects all people with disability as equal and contributing members of the community. For Tasmanians living with autism and their families, friends and carers, access to timely, appropriate services and supports across all life-stages can make a significant difference to their everyday lives as well as their capacity to achieve longer-term life goals. Ensuring adequate provision of such services and supports is challenging, yet critical in meeting the increasing need for people living with autism in Tasmania.

This submission does not seek to address each aspect of the Inquiry's Terms of Reference. Rather, areas of relevance to Tasmanian Government services are highlighted as they relate to the provision of services, supports and life outcomes for people living with autism in Tasmania.

## 2 AREAS OF RELEVANCE

### 2.1 Education

School and other educational settings are important social environments where children learn to interact with their peers, an activity many students with autism find challenging. The Tasmanian Government recognises there are unique opportunities to provide support within educational settings that help develop and enhance the skills important to achieving good educational and life outcomes for children and students with autism.

The Tasmanian Government is committed to implementing best practice autism support for students in Tasmanian Government schools. Six autism specific support classes established across the State, focus on participation and engagement in safe and supportive learning environments. There is also a range of specialist services that support access, participation and engagement of students with autism, including Autism Consultants (AC). ACs are qualified teachers with specific expertise in working with children on the autism spectrum. They provide support and assistance to schools and families; input into planning for individual students;

<sup>1</sup> ABS 4430.0 – *Disability, Ageing and Carers, Australia: Summary of Findings*, 2018

<sup>2</sup> COAG Disability Reform Council Quarterly Report 31 December 2019 Q2 2019-2020

support for appropriate curriculum differentiation and professional learning to support capacity building for staff in schools.

At the beginning of 2019, there were 196 Tasmanian government schools with around 63,000 enrolled students<sup>3</sup>. Student access, engagement and retention are priority areas for the Tasmanian Department of Education (DoE) so that everyone can participate and engage in learning and pursue life opportunities regardless of background, culture, ethnicity, belief, gender identity or level of ability.

#### *Prevalence of autism in Tasmanian Government schools*

The Tasmanian Government notes that of the 205,200 Australians with autism in 2018, males were 3.5 times more likely than females to have the condition, with prevalence rates of 1.3% and 0.4% respectively (ABS 2018).

Based on current ABS prevalence rates, 63,000 students enrolled in Tasmanian Government schools extrapolates to around 630 students with autism (around 1 in 100 people). Information from DoE indicates this figure is higher, estimating there are over 1,000 students with autism in Tasmanian government schools, with some schools having two to four times the number of students estimated based on ABS data.

In regard to distribution across age, DoE data shows there are 339 students with autism in kindergarten to grade two; 420 in grades three to six; 294 in grades seven to 10, and 61 students across years 11 and 12. These figures reflect students known to schools and ACs in 2019. The variation between numbers in primary and secondary years may not be a reflection of changes in distribution so much as a factor of identification, including self-disclosure.

Analysis of data provided by ACs as at December 2019 shows there are 298 students statewide receiving Early Childhood Intervention Services (ECIS) with a diagnosis or pending diagnosis of autism (125 located in the south and 173 in the north). Additional ECIS data indicates the majority of young people in Tasmania are diagnosed at two years of age followed by three years of age as the second most typical age at diagnosis. There are a further 1,119 students in the school-aged population who are known to ACs (716 students in the south and 403 in the north). Although this data is not definitive, as not all students with autism access the services of an AC, it does support the view that the prevalence of autism in Tasmania is higher than that estimated through ABS data.

#### *Levels of Adjustment in Tasmania*

The Tasmanian Government has recently implemented a new needs-based funding model to ensure education funds align with the educational adjustments teachers make in the classroom to assist students with disability to access, participate and engage in quality learning programs. The new model considers the additional and variable needs of students with disability such that those requiring more intensive levels of support attract greater levels of resources compared with those requiring lower levels of support. The model aligns to the Nationally Consistent Collection of Data (NCCD) levels of educational adjustment which include extensive; substantial; supplementary and Quality Differentiated Teaching Practice. In relation to Tasmania, DoE data shows that as at December 2019, 39 students with autism are in the mid extensive

<sup>3</sup> Tasmanian Department of Education Key Data, March 2019

range; 84 in low extensive; 141 in high substantial; 155 in low substantial; 195 in supplementary; and 229 in Quality Differentiated Teaching Practice.

#### *Diagnostic Information*

With regard to diagnosis of autism in Tasmania, DoE data indicates there are differences in the number of young people diagnosed by individual diagnostic agencies. Within the early childhood intervention population, approximately 76 per cent of diagnoses originate from Tasmania's children's therapy service, 16 per cent from paediatricians and eight per cent from the Tasmanian Autism Diagnostic Services.

In summary, the Tasmanian Government observes the prevalence of autism in Tasmania is higher than that indicated by ABS data. As such, planning, resourcing and implementing quality services and programs to effectively meet the needs of students with autism is challenging within Tasmanian government school settings.

The Tasmanian Government continues to monitor current initiatives and engage in learning about the most effective educational provision for students with autism.

## **2.2 Justice**

The Tasmanian Government acknowledges that people with disability often experience barriers accessing justice services. The *Disability Justice Plan for Tasmania 2017-2020* identifies changes to ensure equality before the law for those who may otherwise be denied this fundamental right.

The Office of the Public Guardian (OPG), within the Tasmanian Department of Justice, has made the following comment in regard to some of the Terms of Reference of this Inquiry.

In looking at the adequacy of services to meet the needs of Tasmanians with autism across all life stages, the OPG advises that where there is exceptional complexity, it is not uncommon for services (particularly those operating in a commercial environment) to withdraw supports which can result in people with no specific health need being admitted to hospital to ensure their safety. In the case of psychological supports, the OPG has observed a focus on early intervention for children with less support available for adults across other life stages.

Regarding the interaction between services, the OPG has observed that people with autism often have to "make do" with services designed for people with intellectual and cognitive disabilities, which are often not well aligned e.g. supported employment options can be in busy, noisy environments which may be inappropriate for people who need to avoid sensory overload. Also, a limited supply of appropriate housing, particularly emergency respite accommodation, can result in people with autism requiring hospitalisation for safe accommodation rather than any medical need.

The OPG considers that failure to provide adequate and appropriate services for people with autism, particularly those aimed at increasing independent living skills and developing autonomy, directly affects the degree to which people with autism can participate in community and economic life. Poor or inadequate services can see people with autism living in unnecessarily restrictive environments that do not meet their needs or maximise their potential. This can lead to use of restrictive practices including physical, environmental, personal and chemical restraints.

The appointment of a guardian is often sought at key life transition points, for example, a young person moving into adulthood from state care, or an older adult losing the support of ageing parents. Better services at such times can obviate the need for a guardian. Guardians are essentially substitute decision-makers but will often be sought as a proxy for a case-manager or coordinator. However the appointment of a guardian comes with an inherent curtailment of the person's right to autonomous decision-making and should therefore be an option of last resort.

In looking at the adequacy and efficacy of the NDIS for people with autism, the OPG's primary concern is that NDIS planners do not always have the skills, knowledge, and understanding to effectively support people with autism. This can result in the development of plans deficient in the types of and level of supports needed. Introduction of draft plans may assist in supporting NDIS planners and participants to develop appropriate plans.

Similarly, sufficient capacity and sustainability of advocacy supports for people with autism is critical to ensure the basic tenets of the NDIS, choice and control, are met. The OPG considers it essential for continued provision of advocacy services as absence of such supports may lead to increased use of guardianship, a more expensive and restrictive option than adequately funded advocacy supports.

## 2.3 Health and Human Services

The Tasmanian Government is committed to ensuring that health and human services are provided in ways that are accessible, inclusive and appropriate to the needs of Tasmanians, including those with disability. An *Interim Disability Action Plan 2018-2021* complements work already being undertaken, including work to improve, promote, protect and maintain the health, safety and wellbeing of Tasmanians.

### 2.3.1 Health

In looking at current approaches and barriers to consistent, timely and best practice autism diagnosis the Tasmanian Government notes:

- Tasmanians can experience long wait times for diagnostic assessment (often over 12 months);
- there is a range of workforce issues, most notably the limited availability of paediatric psychiatrists and allied health professionals with the requisite skills and experience to work with people with autism and undertake the assessments required to inform a diagnosis;
- establishment of the NDIS has compounded workforce issues, with many allied health professionals leaving the public service to set up private practices delivering services directly to NDIS participants - this impacts not just on diagnosis but on the availability of services after a diagnosis has been made;
- the Tasmanian Department of Health is working to alleviate workforce issues through:
  - participation on the Workforce Control Oversight Group - a working group under the Market Oversight Working Group (MOWG) which oversees development of a National Disability Workforce Plan; and

- o its work with the University of Tasmania on the Allied Health Expansion Project, which aims to introduce Physiotherapy, Occupational Therapy, Speech Pathology and Dietetics courses from 2022. This work includes building capacity for allied health professionals to work with people with autism in mainstream and disability services funded under the NDIS.

Regarding the interaction between services provided by the Australian Government, state and local governments, it is noted:

- pre-school and school-aged children that access Australian Government funded packages for autism therapy post diagnosis, and who are eligible for NDIS, may find they have limited interaction with health services provided by the Tasmanian Health System (THS);
- any child or adult with autism may be referred to allied health services in the THS and would be assessed for eligibility and clinical priority; and
- generally, children and adults with autism who access other funded services would not be eligible for THS Allied Health services, but may be referred for other non-autism related issues prioritised on clinical need.

### **2.3.2 Human Services**

In looking at current approaches and barriers to consistent, timely and best practice autism diagnosis, the Tasmanian Government funds two key services for people with autism: a statewide children's therapy service and the Tasmanian Autism Diagnostic Service.

#### *Children's therapy service*

The children's therapy service is funded to provide specialised, therapeutic care and services for children with disability, including those with autism. These services are intended to improve, maintain, or slow deterioration of a person's functional performance and to assist in the assessment and recommendation of equipment to enable people to perform as independently as possible in their environment. Services include diagnosis and support of children on the autism spectrum.

The service offers a mix of public and private therapy services including physiotherapy; occupational therapy; speech pathology; psychology; behaviour support and specific autism programs, for example the Autism Specific Early Learning & Care Centre (ASELCC) in the North West of the State. An assessment team accepts referrals from professionals only, and a referral requires two professionals to agree regarding the appropriateness of the referral for Autism Spectrum Disorder Assessment (0-5 years).

#### *The Tasmanian Autism Diagnostic Service*

The Tasmanian Autism Diagnostic Service (TADS) is jointly funded by Department of Communities Tasmania and DoE. TADS core business is to conduct comprehensive autism diagnostic assessments for children aged up to 18 years across the State. Based in Hobart, the service is recognised as the major service provider in autism diagnostic assessment across the State. Referrals are accepted from paediatricians, psychiatrists and psychologists with over 80 per cent of the services referrals coming directly from paediatricians.

The TADS service:

- is the only public service in the State that diagnoses children from birth to 18 years;
- provides comprehensive assessments and recommendations that include a range of educational and treatment options for families and key stakeholders tailored to meet the individual needs of the child, young person and their family circumstances;
- is noted for being innovative throughout its diagnostic assessment process to ensure optimal outcomes for children, young people and their families including working in partnership with families and service providers to address concerns, limitations and barriers to accessing services;
- has specialised practitioners with particular expertise, in particular all practitioners are Autism Diagnostic Observation Schedule (ADOS-2) and Autism Diagnostic Interview-revised (ADI-R) trained with assessment tools recognised as 'gold standard' in autism diagnostics;
- has developed relationships with public paediatric clinics which have resulted in streamlined access to both services and improved communication between families and services; and
- routinely sees siblings of children and undertakes Diagnostic and Statistical Manual of Mental Disorders (DSM) IV reviews in response to NDIS applications.

There has been a notable increase in the rate of referrals to TADS between 2011 (173 referrals) and 2019 (480 referrals) with a marked increase from 2015 onwards which has resulted in lengthy wait times for assessments. This is largely attributed to roll-out of the NDIS from July 2016 where a diagnosis of autism often indicates eligibility for the NDIS, potentially providing access to funding for therapy, behaviour supports, personal care, permanent aids and equipment. Also, given the NDIS requires a severity rating to be applied to each diagnostic profile, any child who has not received such a rating requires additional assessment so severity ratings can be applied. Other possible reasons for the increase in referrals are advised below:

- from 2015, DoE has been piloting and implementing an Educational Adjustments funding model for students with a confirmed diagnosis which has increased demand for diagnostic services;
- forward referrals from the children's therapy service and from stakeholders who may have referred to that service; and
- there is only a small number of private practitioners engaged in autism diagnostic assessment in Tasmania.

In May 2019, the then Minister for Disability Services and Community Development announced an additional one-off funding allocation of \$1 million in 2019-20 for TADS to assist in reducing the wait time for an autism assessment. This enabled TADS to employ additional clinical staff and engage contractors with expertise in autism diagnostics to work in partnership with TADS to undertake autism assessments across the Tasmania.

In considering the interaction between services provided by the Australian, state and local governments, the co-funding of TADs is a good example of an effective interface between government agencies. Other areas worthy of comment as part of this submission are the

availability and suitability of appropriate affordable housing; child safety services and family violence.

### *Housing*

There is a demand for NDIS Specialist Disability Accommodation (SDA) and environments to respond to people with support needs that cannot be met by family or within 'standard' service options. This includes children and adults with autism.

While there has been recent development of SDA options around the State with positive outcomes for NDIS participants, more needs to be done to meet current and future need. There are episodes of hospital admissions and extended stays in hospital for children and adults unable to return to the family home due to factors such as the complex disability needs of the individual (including those with autism spectrum disorder and/or behaviours of concern), stressors experienced by the family and limited available or appropriate accommodation options and services in the area where they live. In these situations, access to suitable accommodation (which includes SDA in the design category of "robust") is required to enable timely discharge from hospital as well as progressing opportunities for shared care between family and NDIS funded residential supports.

Service development for this very specific accommodation response is not typically attractive to property developers or service providers, there remains a responsibility for state governments to plan for the supply of this housing.

*Tasmania's Affordable Housing Strategy 2015 – 25* is a ten year plan to drive housing reform and investment. The Strategy is supported by Action Plans. The current Action Plan 2 (2019 – 2023) contains funded commitments to construct new homes that are purpose built for those participants of the NDIS with complex and exceptional needs who require a tailored form of integrated housing and support. This includes NDIS participants with SDA approved in their plan or who have NDIS Supported Independent Living packages for supported accommodation. The Affordable Housing Action Plans are increasing new supply of affordable rentals or home purchase of properties appropriate for people living with disability or changed mobility due to ageing.

A portfolio plan for SDA will be released under Action Plan 2. This plan will focus on the future management of SDA, the majority of which is owned by the Tasmanian Government (the Director of Housing) and currently head-leased to NDIS registered housing and support providers, who in turn provide secure leases to NDIS participants.

### *Child Safety Service*

The role of the Department of Communities Tasmania's Child Safety Service is to protect children and young people who are at risk of abuse or neglect. In Tasmania, the safety of children and young people is covered by the *Children, Young Persons and their Families Act 1997*.

To enable optimal outcomes, the need for early diagnosis and ready access to appropriate supports is critical when a child with complex disability needs, including autism, is entering Tasmania's out-of-home care system. The Tasmanian Government supports an environment where:

- the most vulnerable children who have entered care due to abuse and neglect receive an the earliest possible diagnosis and treatment options during the early care planning stages;
- current services can adequately respond to competing demands;
- access to private specialists is both timely and affordable;
- NDIS plans fully consider and reflect the support needs of children in out of home care with complex disabilities including autism; and
- there is a recognised need for, and availability of specialised training for the broader service sector and key stakeholders working with children with complex disabilities including autism in, or at risk of entering, out-of-home care.

#### *Family Violence – Children and Young Persons Program*

The Tasmanian Government's Family Violence Counselling and Support Services (FVCSS) funds specialised services to assist Tasmanians affected by family violence. This includes the Children and Young Persons' Program (CHYPP). CHYPP counsellors provide a range of statewide services to address the impacts of family violence, through child/caregiver sessions, one on one counselling, group programs, support for care givers for parenting after violence and the provision of psychological services.

The CHYPP advises that children with autism who are also affected by family violence trauma often present differently to the service which can, in some cases, may impact on the assessment of a child's needs. An assessment of the interactions between trauma impacts and autism is essential to make sure an appropriately tailored therapeutic response is developed. For example, children with autism and trauma may have different capacity to engage in abstract story, metaphor, play or symbolic based therapies and sensory issues can impact on using modalities such as sand and symbol therapy or Eye Movement Desensitisation and Reprocessing (EMDR) techniques. They also may have specific needs in relation to eye contact, sensory soothing activities, communication, food, structure and interests which can be incorporated into the therapeutic sessions.

CHYPP has observed that in responding to individual need, a clear framework is important along with access to specific resources that assist children with autism to engage fully in the therapeutic process in recovering from family violence trauma.

## **2.4 Advocacy**

Advocacy services are critical in helping ensure people with disability can enjoy the same rights and access the same services as others. The Tasmanian Government has committed to support independent individual advocacy to protect the rights of people with disability, with continued funding for individual advocacy services until the end of June 2021.

Historically funded by the Tasmanian Government, peak body Autism Tasmania seeks to improve community awareness, acceptance and understanding of autism across the State. It is pleasing to note Autism Tasmania's recent success in National Disability Insurance Agencies (NDIA) Information, Linkages and Capacity Building (ILC) funding rounds, receiving more than \$2 million to provide specialist and relationship based materials, information, linkages and

referral as well as additional funding for peer support. Autism Tasmania is also part of a consortia of state-based autism peaks that have been successful in the ILC National Information Program grant round for a project called Autism Connect, a one-stop-shop providing independent evidence-based information, advice and assistance to people with autism, their families, professionals and the NDIA.

The Tasmanian Government acknowledges the critical role that advocacy services play in improving the lives of Tasmanians with autism, their families and carers and supports ongoing funding through the NDIA's ILC program.

### 3 CONCLUSION

The Tasmanian Government recognises that for Tasmanians with autism and their families, friends and carers, access to quality, timely and appropriate supports across all key life-stages can make a positive difference to their everyday lives. Failure to provide such supports across mainstream services including education; justice; health; mental health; children and youth services and housing, has a significant economic and social cost, not just for Tasmanians with autism but for Tasmania as a whole as it strives towards a fully inclusive society that values and respects all people with disability as equal and contributing members of the community.

In providing information relevant to this Inquiry, the Tasmanian Government offers the following as a summary of the key points:

- The Tasmanian Government observes the prevalence of autism in Tasmanian government schools is higher than that indicated by ABS data. As such, planning, resourcing and implementing quality services and programs to effectively meet the educational needs of students with autism is challenging within Tasmanian government school settings;
- In looking at the adequacy and efficacy of the NDIS for people with autism, there are concerns NDIS planners do not consistently demonstrate the skills, expertise and knowledge to adequately support people with autism, which can result in plans being developed that do not respond to participants needs. Introduction of draft plans may help to improve planning outcomes for participants with autism;
- While there has been recent development of accommodation for people with disability across the State, more needs to be done to respond to the demand for Specialist Disability Accommodation to meet the individual needs of people with autism;
- Workforce issues, most notably the limited availability of clinical and allied health professionals (in both public and private settings), with the requisite skills and experience to successfully support people with autism and undertake the assessments required to inform a timely diagnosis is a key concern for the Tasmanian Government;
- The Tasmanian Government notes the importance of early diagnosis and access to appropriate supports for all people with autism and, in particular, children entering Tasmania's out-of-home care system and those affected by family violence. There is also a need for specialised training for key stakeholders working with children with autism; and

- The Tasmanian Government acknowledges the critical role that advocacy services play in improving the lives of Tasmanians with autism, their families and carers and supports ongoing provision of such services.