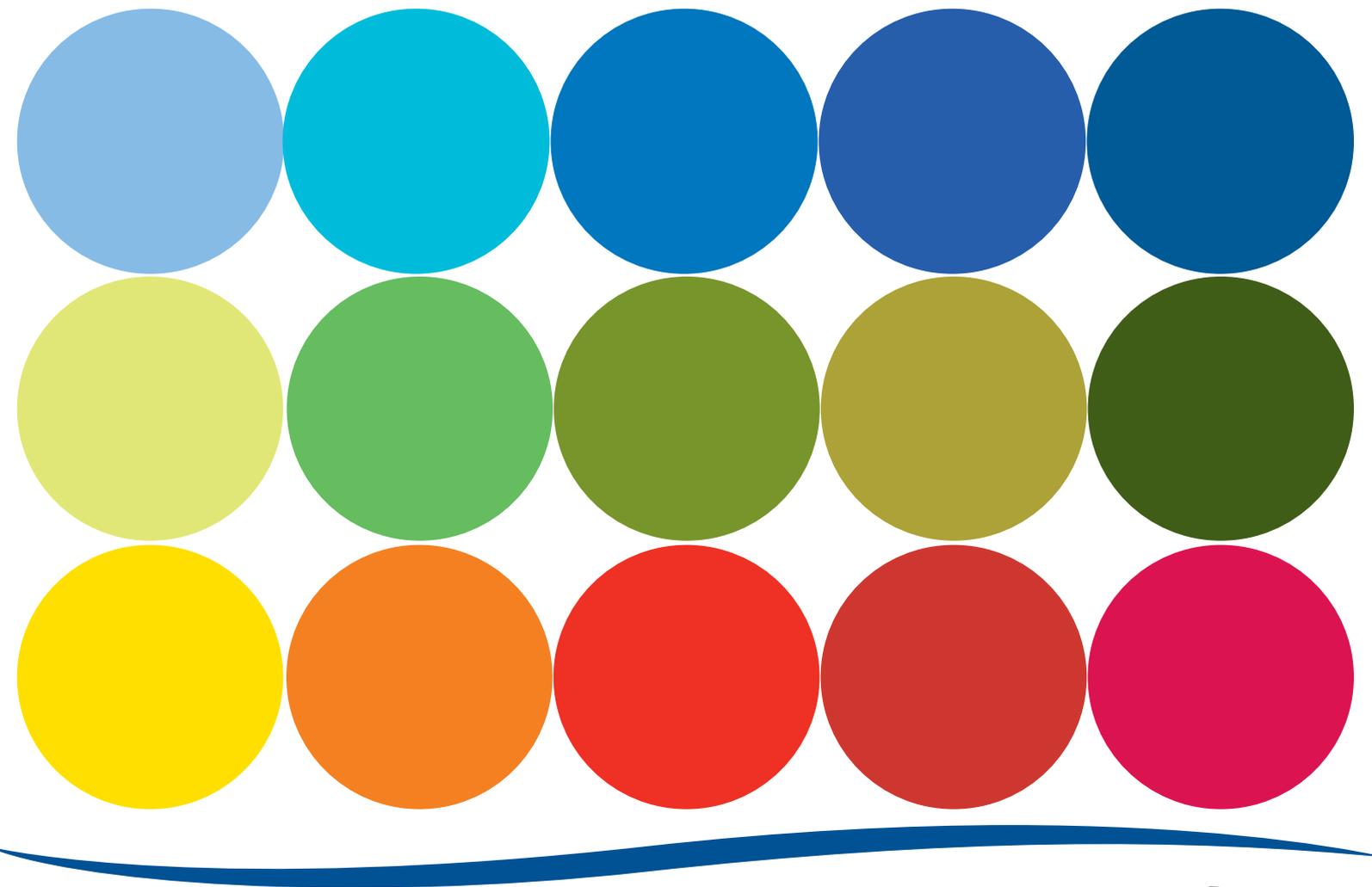


Autism Advisory Panel Final Report

2018



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Thanks

The Autism Advisory Panel (the Panel) has comprised of many members, government representatives and guests over its four-year term. Their participation has been entirely voluntary and invaluable in contributing to the work achieved by the Panel since 2014. We would like to formally thank and acknowledge the following people:

Cassie Xintavelonis (le Fevre) – Chairperson

Terry Burke – Deputy Chair

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Chairperson's Foreword

In 2014, the Minister for Human Services, the Honourable Jacqui Petrusma, invited some of the state's most experienced and knowledgeable individuals from the Tasmanian Autism Community to form the Autism Advisory Panel (the Panel). The Panel has consisted of representatives from a range of backgrounds. Most importantly, people on the autism spectrum are represented as well as other consumer representatives including parents of children and young people on the autism spectrum. The Panel has also included a variety of allied health professionals, members of support and advocacy organisations, researchers and educators.

The makeup of the Panel has changed over its lifespan due to changing commitments and circumstances. I think it is important to note that the Panel members are all volunteers and have given their time and expertise freely, often in addition to their regular workloads, and I would personally like to thank each and every member for their valuable contributions and attendance at monthly, and more recently bi-monthly, meetings.

I would also like to acknowledge the support and contribution of representatives from the Department of Health and Human Services as well as the Department of Education who have informed and supported the Panel over the past few years. I would especially like to thank Angela Proposch for her role as Project Officer for the first few years and Dianna King for taking over the position in 2017.

The Panel has been guided by Terms of Reference that were developed prior to the Panel's formation in 2014, prior to the commencement of the rollout of the National Disability Insurance Scheme (NDIS) and just after the establishment of The Cooperative Research Centre for Living with Autism (Autism CRC). The Terms of Reference are relatively broad and address the needs of people on the autism spectrum across the lifespan, however the focus of the Panel has changed somewhat over the past few years, especially given the changing landscape that has come from the introduction of the NDIS, as well as the opportunity to become involved with the world's first national, cooperative research effort focused on autism, the Autism CRC.

There have been a number of recurrent issues raised during the life of the Panel. These issues are not unique to Tasmania but clearly have an impact on many members of our community. The need for early diagnosis and consistent diagnostic practice has been a strong theme throughout the past three and a half years. The Panel has followed closely the development of the Autism CRC's National Guideline for Autism Spectrum Disorder (ASD) diagnosis in Australia and were unanimous in recommending Tasmania's involvement in the Social Attention and Communication Surveillance – Revised (SACS–R) in order to encourage early surveillance and therefore early diagnosis of Autism Spectrum Disorder. The Panel is also acutely aware of growing wait times for diagnostic services and the lack of publicly funded adult diagnostic services and has made several recommendations for increased support for these services.

While the introduction of the NDIS has seen a move away from state-funded intervention services, the Panel is aware that workforce retention and lack of service provision (both public and private) is an issue that extends beyond the scope of the NDIS.



The lack of tertiary training in Tasmania for allied health professionals (including speech pathology, physiotherapy and occupational therapy) results in difficulties attracting and retaining trained professionals from these disciplines across the state. The demand for services also makes it difficult to fill positions in more rural and remote areas of the state.

The need for increased awareness and acceptance of Autism Spectrum Disorder is another key issue for the Panel. Several recommendations have been developed to address this including the need for comprehensive and evidence-based autism-specific training for frontline workers and professionals who provide direct services to people on the autism spectrum including health and education professionals. The Panel has also recommended the development of local awareness campaigns and the introduction of an accreditation process for events and businesses to become 'autism-friendly'.

Overall, the importance for consistency across government departments has been identified as a critical issue with individuals often having to replicate reports or provide additional or differing information in order to provide evidence of a diagnosis and/or evidence of impaired functioning. This is not only time consuming but can increase the financial burden on individuals and families and create confusion among professionals. As a result, the Panel has recommended the acceptance of consistent policies across departments in terms of diagnosis and criteria for eligibility of services.

While the submission of this report effectively marks the conclusion of the Autism Advisory Panel, it is hoped that the state government continues to consult and seek advice from members of the autism community in Tasmania in years to come and continues to work towards a whole of government strategy for people on the autism spectrum across the lifespan.

Cassie Xintavelonis

Executive Summary

The Autism Advisory Panel (the Panel) was established in June 2014 as part of a state government election commitment to develop a long-term autism strategy that met the needs of Tasmanians across their life span. The Panel was governed by a Terms of Reference (ToR) (see Attachment 1) with the role and function of:

- 1 Examining and recommending best practice early intervention models that support children with autism, their families and carers, including the practicalities of access to the new web-based Rethink Autism program to ensure maximum use by parents, guardians, teachers, teacher assistants, child care organisations and others who support the child.
- 2 Assessing the viability and benefits of clinics that assess, and treat, autism and the many co-morbidities of autism and working closely with established services such as epilepsy support services.
- 3 Considering the professional development of health personnel, emergency services, education workers and other professionals in relation to how to best interact with people living with autism, and how to provide for inclusive support services for this population, including the introduction of a protocol, such as Autism Speaks.
- 4 The best means of delivering awareness, education and practical help for families and carers.
- 5 Seeking input from relevant organisations, professionals, families and carers caring for people with autism (and individuals with autism themselves) in addressing the terms of reference.
- 6 To develop a whole of government autism strategy for Tasmanians living with Autism Spectrum Disorder from birth and throughout adulthood. This strategy will identify gaps, service system issues and recommendations to the Minister for future service delivery models whilst describing the interface with the NDIS in the transition to full-scheme in Tasmania.
- 7 To provide a final report to the Minister for Human Services outlining the above.
- 8 Other matters hereto seen as relevant.

The Panel had a diverse range of members including representatives from the Department of Health and Human Services (DHHS), Department of Education (DoE), parents, consumer representatives, community sector organisations and private practitioners. Additionally, a range of 'critical friends' was invited onto the Panel for discussions on specific matters. Examples of these critical friends include paediatricians and representatives from the Child Health and Parenting Service (CHaPS). Over the four-year term the Panel met regularly and published frequent communiques via the DHHS website, outlining the broad key messages and actions of each meeting.

Since its inception the Panel supported a range of activities and projects including:

- a pilot of Rethink Autism in collaboration with schools
- a partnership with the Cooperative Research Centre for Living with Autism (Autism CRC)
- a research trial to support the *Social Attention and Communication Surveillance - Revised (SACS-R)* to assist in improved early detection and diagnosis of Autism Spectrum Disorder (ASD).

The Panel during its four-year term has also witnessed some major changes to provision of support for Australians with disability, their families and carers with the trial and subsequent transition to full-scheme of the NDIS. In Tasmania approximately 35 per cent of NDIS participants to date have a primary diagnosis of ASD. The transition to the NDIS is seeing funding models shift from block funding to individualised funding models, a change in state responsibilities in funding disability services and a change in opportunities for people on the autism spectrum.

At a state government level, the *Disability Framework for Action 2013–2017: a Tasmanian government plan for people with disability* is being updated and modified and the *Disability Services Act 2011* is currently under review. These all have the potential to have significant impact on people on the autism spectrum and their families.

Within the research sector, in 2013 the Autism CRC was established in an effort to provide the national capacity to develop and deliver evidence-based outcomes through its unique collaboration with the autism community, research organisations, industry and government. Substantial research has been invested in developing a proposed assessment and diagnostic guideline - *The diagnostic process for children, adolescents and adults referred for assessment of autism spectrum disorder in Australia: National guideline draft for community consultation* (National guideline) in Australia.

The activities of the Panel and other influencing factors have shaped the recommendations that have been developed as a part of this report.

The Panel has made the following recommendations against the Terms of Reference (ToR).

Recommendations

ToR 1: Examining and recommending best practice early intervention models including implementation of Rethink Autism

- 1.1 Increase resource allocation to assessment services.
- 1.2 Continued use of the *Social Attention and Communication Surveillance – Revised (SACS-R)* tool through CHaPS to lower the age of identification of children at risk of having autism.
- 1.3 Reinstate the CHaPS checks at 18 months of age statewide, as this is a crucial age in childhood development.
- 1.4 As a result of the introduction and subsequent transition to the NDIS and the limited uptake of the pilot of *Rethink Autism*, it is recommended that bulk contracts are no longer purchased and that current users who wish to continue are able to purchase an individual licence themselves.

ToR 2: Assessing viability and benefits of clinics for assessment and treatment

- 2.1 Support from the state government to implement *The diagnostic process for children, adolescents and adults referred for assessment of autism spectrum disorder in Australia: National guideline*.
- 2.2 Provide incentive and opportunities for allied health staff with skills, experience and desire to work in the field of autism diagnosis within Tasmania by providing bonded scholarships for professional development for clinicians to attend training for the Graduate Certificate in Autism Diagnosis in Western Australia or similar.
- 2.3 Initiate best practice standards and aim for a wait time from referral to assessment service to commencing assessment of no longer than three months.
- 2.4 Establish a state funded adult autism assessment service for people aged more than 18 years.
- 2.5 The Tasmanian Government use its position on the COAG Health Council to urge the Australian Health Ministers' Advisory Council (AHMAC) and the Commonwealth Department of Human Services to remove the age cap for the Medicare rebate for the diagnosis and assessment of ASD.

ToR 3: Consider professional development of mainstream front-line workers and other professionals

- 3.1 Establish a training program for new teachers, nurses, medical practitioners, allied health and paramedic workers to access autism specific training.
- 3.2 Develop an online training program/information campaign for all front-line workers and professionals, to include private sector, community and disability workers.

ToR 4: Delivering awareness, education and practical help

- 4.1 Develop a public awareness campaign for the Tasmanian community about people on the autism spectrum and their needs.
- 4.2 Develop an endorsed 'Autism Friendly' accreditation for businesses and services to assist in promoting positive images of people on the autism spectrum to improve community understanding.

ToR 5: Input from relevant organisations, professionals, families and carers

- 5.1 The Tasmanian Government establish an advisory panel for consultation into the future consisting primarily of people on the autism spectrum and their families to help guide and steer the future development of policies, services and supports that affect them.

ToR 6: Whole of Government strategy

- 6.1. Undertake a desktop review of the available data relating to participants on the autism spectrum in the NDIS and the outcomes they are achieving, including the outcomes in mainstream services.
- 6.2. Establish ongoing biannual targeted interviews with people on the autism spectrum and their parents/carers to assess the outcomes achieved, including access and inclusion in mainstream services.
- 6.3. Include an autism-specific focus in the *Disability Services Strategic Plan 2019–2021*.
- 6.4. Include autism specific actions to improve access to services and outcomes for people on the autism spectrum in the *Disability Framework for Action and Department of Health and Human Services (DHHS) Disability Strategic Plan*.
- 6.5. Include autism specific actions to improve access to services and outcomes for people on the autism spectrum, their families and carers in the *Tasmanian Carer Action Plan 2013–2018*.
- 6.6. Establish a government-wide acceptance of what constitutes a diagnosis of autism to reduce duplication and unnecessary assessments for people accessing services across various departments.
- 6.7. Establish a consultation group that meets at least quarterly to review Autism CRC research opportunities and projects to make recommendations to the state government about participation in these activities.

Language

Language can be a powerful tool in shifting community attitudes and driving outcomes for people with disability. People with a lived experience of autism have the right to choose their preferred description, including people with autism, people on the autism spectrum, and autistic people. It is understood that there is a mix of views about the best way to describe autism with an emerging preference for Identity-First language (e.g. autistic children and adults) documented internationally¹ to be the preferred language of many people on the autism spectrum and their parents. For the purpose of consistency throughout this report the term 'people on the autism spectrum' has been used.

¹Kenny, L., et al. (2016) *Which terms should be used to describe autism? Perspectives from the UK autism community*. *Autism* 20 (4): 442 - 462

Autism Advisory Panel Activities

• Rethink Autism

Rethink Autism (Rethink) is a web-based program developed in the United States, designed for schools and parents to use with students on the autism spectrum. The program is based on the philosophy and techniques of Applied Behaviour Analysis (ABA), an evidence-based intervention for ASD. ABA was originally designed as an intensive early intervention technique for pre-school aged children with expected positive outcomes for intellectual functioning, language development, daily living skills and social functioning. Empirical studies have demonstrated the effectiveness of ABA, and thus it is assumed that Rethink itself is likely to be effective².

As a part of the State Government's commitment to autism support, Rethink was piloted in Tasmania (2015 – 2018). The Panel identified four schools and one service which would initially engage with the program – the Autism Satellite Learning Centre at Lindisfarne North Primary School, Mountain Heights District School, Waverley Primary School, Clarence High School and the Early Childhood Intervention Service South.

In April 2015 the DHHS signed a service agreement with Rethink to provide a web-based service and remote consultation and purchased a site software licence for a two-year subscription for a cost of \$153 612. In March 2017 the licence was renewed for a further 12 months at a cost of \$76 027. The licence provides for up to 60 participant places in the Rethink program and unlimited access to a range of online professional learning and teaching resources for educators, parents and carers.

To date, 51 licences out of the possible 60 were accessed since the program commenced, however only an estimated 25 per cent of licenses were actively used. One out of the five services initially targeted took up the program, and significant effort went into opening up the program to students at any educational facility in Tasmania, spanning Catholic, Independent and public schools – including e-school and home schooling.

It is important to note that the utilisation of the program was not solely based on filling the 60 licences but also on providing resources and materials to parents and teachers to assist them in supporting children on the autism spectrum. At time of writing more than 100 profiles were created to allow people access to the program. This may indicate they signed up students and were able to access Rethink materials, resources and training to inform their education approaches.

An evaluation into the implementation of Rethink was completed by the University of Tasmania (UTAS) in March 2017. The relatively low Rethink participation rate was reflected in low evaluation participation. Only 18 out of 136 people contacted responded to the evaluation. Due to the small number of responses the evaluation was unable to provide a generalisation of views. It did, however, reveal differing views and feedback around the program's usability and fit within the Department of Education (DoE).

²Cheek, C., King, A., Woodroffe, J., Allen, P. & Stephens, M. (2017) FINAL REPORT Evaluating Engagement with Rethink Autism in Tasmania. UTAS

The evaluation demonstrates mixed responses and individual views on the program's benefits. Respondents consistently identified the amount of time required to understand the program and to implement it in the classroom. They questioned if it was compatible with a mainstream classroom, and the uncertainty of its relevance to higher-functioning and older students. Respondents mostly found the content of the website to be understandable. Respondents indicated a high level of support from the state's Rethink Coach and also valued the goals, expertise and comprehensiveness of Rethink. The addition of the Rethink Coach was a local response. It was an initiative of the Panel to try to further support the implementation of Rethink, however it was not part of the model initially discussed. Without the work of the Rethink Coach the uptake rate would most likely have been less. Despite the flexibility taken by DHHS and DoE in the approach to implementation of Rethink, there was little increase in the uptake and program retention proved difficult. The advantage of relative affordability apparently offered by the online program was decreased by the local implementation of the Rethink Coach.

• **Prevalence Study**

The Panel's initial ToR called for a prevalence study of people on the autism spectrum in Tasmania to be completed. Initial investigations commenced with DoE and Catholic Education to gain insight into the number of students enrolled in educational programs who had disclosed a diagnosis of ASD. This information was challenging to establish. Following further review of current evidence and Australian Bureau of Statistics data and discussions with Autism CRC, it was decided that it would be prudent to postpone a prevalence study until appropriate resources could be allocated to create a research study.

• **Service Mapping**

In order to establish what services were available for people on the autism spectrum and their families, a service map was created identifying what services were available for diagnostic assessments, therapeutic intervention, transition support, employment services and aged care options. The service map also identified where the service gaps were (which regions had limited or no services or increased wait times) across both the public and private sector.

As the transition to full-scheme NDIS commenced in Tasmania, it became apparent that the service provision of therapeutic intervention, employment services, and some transition support would be funded for individuals by NDIS. The service mapping then became focussed on state government funded services, in particular diagnostic assessment services.

• **Autism CRC**

The Tasmanian State Government and the Panel entered into a partnership agreement with Autism CRC from September 2016–2021 to establish a research base in Tasmania. The Autism CRC was established in 2013 and is the world's first national, cooperative research effort focussed on autism. The Autism CRC develops and delivers evidenced-based outcomes through collaboration with the autism community, research organisations, industry and government. The financial contribution of this partnership agreement is \$50 000 per year alongside in-kind contributions totalling an overall commitment in excess of \$800 000 over five years.

The partnership with Autism CRC allows Tasmania to stay at the forefront of research and contribute to studies on an international scale. It is recommended that the state government fund a position to manage the partnership with the CRC and Tasmania's strategic participation in autism research.

• **Social Attention and Communication Surveillance – Revised (SACS–R)**

The *Social Attention and Communication Surveillance (SACS)* tool has been developed and researched over the past 10 years in Australia. Data has been collected in this time on more than 30 000 children by maternal child health nurses across regions of Melbourne, Victoria during their 12, 18 and 24-month routine child health consultations. SACS has undergone a revision (SACS–R) and research continues within Victoria following up these children. This research has confirmed diagnostic stability at preschool and school age. Overall, published results demonstrate high rates of positive predictability, sensitivity and specificity. Additionally, rates of negative predictive validity will be determined after completion of the Victorian study in 2017.

The Tasmanian arm of this research project is a partnership between DHHS, UTAS, the Olga Tennison Autism Research Centre at La Trobe University and the Autism CRC. The results of the proposed study are expected to further contribute to this growing body of evidence for the use of the SACS–R as a community-based developmental surveillance approach to monitor young children. This will allow for additional unique comparisons within a rural and regional state.

The SACS–R is regarded as the most reliable and predictable tool for identifying children at risk of ASD. For typically developing children this tool has been found to take no additional time to complete within the routine CHaPS child health checks, only requiring additional time should the child demonstrate atypical development.

• **Forums on the Lived Experience of Autism in Tasmania**

The panel contracted Banks Spencer Consulting to undertake a series of focus groups around Tasmania to learn from people on the autism spectrum and parents/carers their experiences in gaining a diagnosis, accessing services and engaging with the community.

A total of five focus groups was held with 13 people attending in Burnie, Launceston and Hobart. While participants recounted different lived experiences, some consistent themes emerged about:

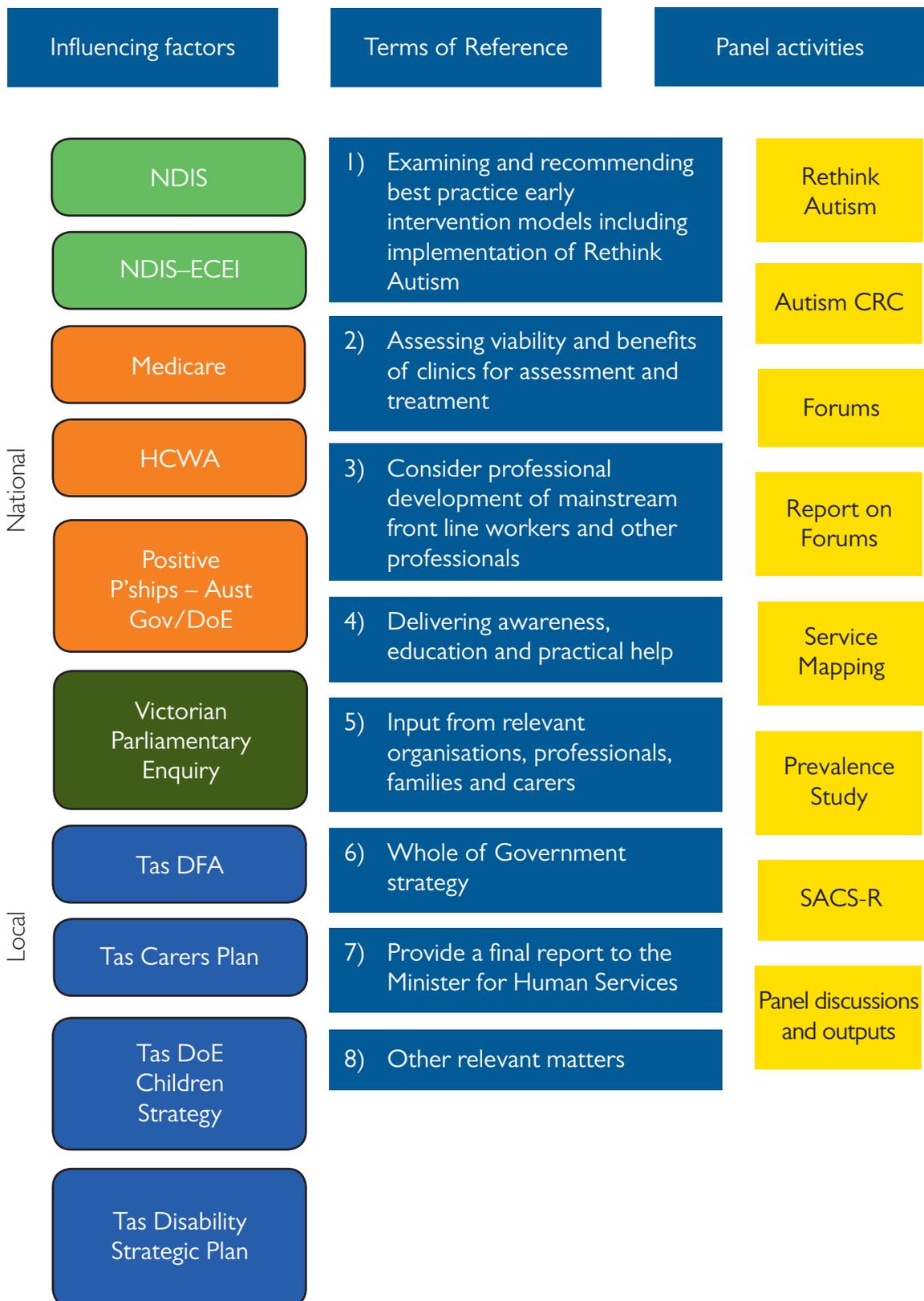
- grief at time of diagnosis
- difficulties accessing services
- the need for identified 'autism friendly' services.

The themes that emerged from the forums are similar to other bodies of work from interstate.

A total of eight recommendations came from the forums, including regular surveys to collect quantitative data regarding:

- service uptake
- provision of post-diagnosis support
- expansion of diagnostic services to include people over 18 years
- access to self-advocacy opportunities.

Diagram 1: Terms Of Reference Map and Panel's Activities



Influencing Factors

Transition to NDIS

The NDIS is new to disability service provision in Australia and provides a set of agreements that ensures that there is a single consistent scheme for the provision of disability support services across Australian states and territories. It allocates funding to individuals who are then able to choose their own services mix and purchase from approved providers. The NDIS will essentially mean the end to 'block funding' from government to service providers. It is expected that the scheme will be fully operational in most jurisdictions and the sector transition complete by 30 June 2019. As of 1 January 2018, people in Tasmania aged 4–34 years have transitioned or are in the process of transitioning to the NDIS scheme. The remaining cohort for early intervention in Tasmania, children aged 0-3 years will transition to the NDIS commencing July 2018. Existing funding programs remain in place until such time as the NDIS is operational.

In preparation for the pending full-scheme transition, state, territory and commonwealth governments have agreed to principles (Applied Principles and Tables of Supports) to determine the responsibilities of the NDIS and mainstream services into the future.

The Applied Principles clearly state that:

- health systems are responsible for funding time-limited, recovery-oriented services and therapies (rehabilitation)
- NDIS has responsibility for supports required due to the impact of a person's impairment on functional capacity and ability to undertake activities of daily living.

Therefore for some children on the autism spectrum, provision of therapeutic support should now be funded by the NDIS rather than the Tasmanian Government.

NDIS ECEI Framework

There has been significant national design work undertaken in collaboration between experts in states and territories to guide best practice provision of early intervention and therapeutic support under NDIS funding. This includes the new NDIS Early Childhood Early Intervention (ECEI) Approach and the *National Guidelines for Best Practice in Early Childhood Intervention* developed by the *Early Childhood Intervention Australia* (ECIA) peak body.

The ECEI approach supports children with developmental delay or disability aged 0–6 years and their families/carers. It addresses skills development needed to take part in daily activities and achieve the best possible life outcomes.

In Tasmania on 1 July 2017 the ECEI approach was introduced for 4–6 year olds. From 1 July 2018, Early Childhood Partners will be assisting children aged six years and under to access the most appropriate supports in the local area.

Early Childhood Partners will provide some short-term intervention and help with requests for access to the NDIS if longer-term early childhood supports are required. During transition to full-scheme the state government has committed to continue in-kind support of existing services to ensure continuity of services for children until the NDIS is fully implemented.

The NDIS has engaged Early Childhood Partners around Australia to deliver the ECEI approach. Early Childhood Partners are organisations experienced in providing

early childhood intervention. In Tasmania Mission Australia and BaptCare are the appointed Early Childhood Partners.

Tasmanian Government Policy and Action Plans

The *Disability Services Act 2011* (the Act) provides the legislative basis for disability service provision in Tasmania. The Act serves to define disability and eligibility for services and includes people with intellectual, psychiatric, sensory or physical impairments, as well as individuals with cognitive impairments who fall within the equivalent Commonwealth legislation. This includes people whose disabilities:

- are permanent or likely to be permanent
- result in substantially reduced capacity of the person for communication, learning or mobility
- require continuing support services
- may or may not be of a chronic nature.

The Disability Services Strategic Plan is a requirement of the Act and sets a vision for the future of specialist disability services in Tasmania. At a time of significant change and reform this Strategic Plan sets the agenda for action. The plan supports the *Disability Framework for Action 2013-2017* (DFA), which embeds the rights of Tasmanians with disability into the work of all state government agencies and provides direction to improve participation by people with disability in social, economic and cultural life.

The DFA is the State Government's response to the *National Disability Strategy 2010-2020* and directs government actions to understand, recognise and remove barriers to equitable access for people with disability and achieve a vision of a fully inclusive society in which people with disability are valued and respected as equal members of the community.

The strategy covers six outcome areas:

1. Inclusive and accessible communities – the physical environment including public transport; parks, buildings and housing; digital information and communications technologies; civic life including social, sporting, recreational and cultural life.
2. Rights protection, justice and legislation – statutory protections such as anti-discrimination measures, complaints mechanisms, advocacy, the electoral and justice systems.
3. Economic security – jobs, business opportunities, financial independence, adequate income support for those not able to work, and housing.
4. Personal and community support – inclusion and participation in the community, person-centred care and support provided by specialist disability services and mainstream services; informal care and support.
5. Learning and skills – early childhood education and care, schools, further education, vocational education; transitions from education to employment; life-long learning.
6. Health and wellbeing – health services, health promotion and the interaction between health and disability systems; wellbeing and enjoyment of life.

The Tasmanian Government has developed a new DFA, *Accessible Island: Tasmania's Disability Framework for Action 2018-2020*.

The *Tasmanian Carer Policy (2016)* aims to recognise the commitment of Tasmanian carers and support them in their caring role as well as supporting active participation in economic, social and community life for themselves and the people for whom they care. The *Tasmanian Carer Action Plan 2013-2018* supports the implementation of the *Tasmanian Carer Policy*. The Policy aims to increase recognition of carers, improve services and support to carers and

to use carers' care-provision experience to inform services and service delivery.

Helping Children with Autism

Accessing government funded ASD specialised services has been via the Helping Children with Autism (HCWA) initiative, implemented by the Australian Government in 2008. This initiative was aimed at early intervention for children aged up to seven years of age (if the child had been registered prior to their sixth birthday). Accessing HCWA funding, up to a total maximum of \$12 000, was dependent on an eligible diagnosis. The initial intention of the HCWA funding was to complement existing state-funded mainstream services rather than replace them. Under HCWA, once aged over six years, the initiative provided for some access to diagnosis support for children up to 13 years, as well as development of a treatment plan, through items on the Medicare Benefits Schedule. As the NDIS is implemented nationally across all age groups the HCWA initiative, along with other early intervention initiatives, is being transitioned to the NDIS.

Victorian Parliamentary Inquiry

In June 2017 the Victorian Government released a Final Report from its *Inquiry into Services for People with Autism Spectrum Disorder*. In December 2017, the Victorian Government provided its response which included:

- immediate funding towards a public education campaign
- improving transition to NDIS
- more resources and training for maternal and child health nurses to help them identify early signs of ASD and refer children for diagnosis earlier
- improving supports for children on the autism spectrum in the school system
- developing a responsive workforce
- creating inclusive sport and recreation opportunities
- more support for rural and regional communities
- supporting girls and women on the autism spectrum.

ToR 1: Examining and recommending best practice early intervention models including implementation of Rethink Autism

At a Glance

Background

Research demonstrates that early intervention or support should start as soon as autism is diagnosed and the family is ready. Early intervention for a child with a developmental delay or disability in their early years is critical to achieving the best outcomes. A family centred approach that supports greater inclusion in mainstream settings and builds the capacity of a child and their family is proven to have positive effects in early childhood intervention.

Until recently state and territory governments were responsible for funding publicly available early intervention services. The NDIS will henceforth be responsible for provision of early childhood intervention services across Australia alongside some continuing state based and private services.

Tasmanian Context

The Tasmanian Government has highlighted in its Disability Framework for Action 2013–2017 that it aims to strengthen the focus of early childhood initiatives for children with disability.

1 July 2017 saw the introduction of NDIS Early Childhood Early Intervention Approach (ECEI) in Tasmania for 4–6 year olds.

The DoE has recently launched *Tasmania's Strategy for Children – Pregnancy to 8 years 2018–2021* which includes extensive Whole of Government and community consultation in order to best support all children and families.

Rethink Autism recently underwent a pilot trial in Tasmania as a part of the state government election commitment.

As a part of the newly established partnership with the Autism CRC, a Tasmanian branch of a research project on the SACS–R tool has been established. The SACS–R research project is identifying children with ASD earlier and allowing access to funding schemes and treatment options earlier.

Recommendations

- 1.1 Increase resource allocation to assessment services.
- 1.2 Continue use of *Social Attention and Communication Surveillance–Revised (SACS–R)* tool through CHaPS to lower the age of identification of children at risk of having autism.
- 1.3 Reinstate the CHaPS checks at 18 months of age statewide, as this is a crucial age in childhood development.
- 1.4 As a result of the introduction and subsequent transition to the National Disability Insurance Scheme and the limited uptake of the pilot of Rethink it is recommended that bulk contracts are no longer purchased and that current users who wish to continue are able to purchase an individual licence themselves.

Research demonstrates that early intervention or support should start as soon as a delay is recognised and the family is ready. Evidence suggests ‘younger age was associated with greater improvements, though effects were not always consistent’³. Recent scientific evidence shows that early experiences shape lives by affecting the way the young brain develops. What happens in the early years has a major effect on health and social development through to adulthood. Therefore it is important that children’s early experiences are positive and that they have a secure foundation for development.

The early years are equally important for children with disability and developmental delay, indeed critical for the whole family. This is when families can best begin to learn how to support and nurture their child, meet their child’s needs, and adapt positively to having a child with disability and/or developmental delay.

In 2016 the NDIA commissioned the report *Autism Spectrum Disorder: Evidence based/ evidence informed good practice for supports provided to preschool children, their families and carers*, prepared by Jacqueline Roberts and Katrina Williams⁴. Its key findings were:

- Parents/carers of children on the autism spectrum should be supported during the early intervention years
- Supports for children on the autism spectrum should be evidence-based and delivered using a family-centred approach that incorporated individual planning

- The specific early intervention program chosen would take into account family preferences and capacity and each child’s strengths and difficulties, age, stage and development
- Support goals for the child on the autism spectrum were to improve social communication and minimise behaviours that challenge to enhance learning and participation
- Early intervention should be provided by autism-trained staff using programs that involve allied health professionals in individual planning, program implementation and review
- Support is sufficiently flexible that it can be adapted and modified in line with the child and parents’ strengths and needs.

As the NDIS rolls out across Australia, early childhood intervention services will be delivered via that scheme under the auspices of the independent statutory agency National Disability Insurance Agency (NDIA) whose role it is to implement the NDIS.

Disability Framework for Action

In its DFA the Tasmanian Government aims to strengthen the focus of early childhood initiatives for children with disability. Specifically it aims to provide access to timely, comprehensive and effective early intervention for people with disability.

³ Weitlauf A.S., McPheeters ML, Peters B, Sathe N, Travis R, Aiello R, Williamson E, Veenstra-VanderWeele J, Krishnaswami S, Jerome R, Warren Z. *Therapies for Children With Autism Spectrum Disorder: Behavioral Interventions Update*. Comparative Effectiveness Review No.137. Rockville, MD: Agency for Healthcare Research and Quality; 2014.

⁴ Roberts, J., Williams, K., Smith, K., & Campbell, L. (2016) *Autism Spectrum Disorder: Evidence-based/ evidence informed good practice for supports provided to preschool children, their families and carers*. NDIS

NDIS ECEI Approach

As Tasmania transitions to full-scheme NDIS, there is a shift in services funded by the state government. The DoE currently funds a state Early Childhood Intervention Service (ECIS) for children aged 0-5 years experiencing developmental delays in two or more developmental areas. DoE has agreed to continue this service until December 2019 to ensure comprehensive services for young children and their families through transition phases. It is important to note that under full-scheme NDIS the current functions of ECIS will be provided by both ECEI and DoE services. This means therapy will fall under NDIS ECEI, and transition to school for successful mainstream schooling will remain a state funded responsibility. DoE has also recently launched *Tasmania's Strategy for Children – Pregnancy to 8 years 2018–2021* which includes extensive Whole of Government and community consultation in order to best support all children and families.

Rethink Autism

There have been some success stories regarding the use of Rethink within a school setting. They include:

- positive responses around access to resources and behaviour support
- visual resources and data recording in order to track progress.

General feedback from participating schools was that the program provided valuable resources and planning options that were appealing to teachers and more specifically teacher assistants (TA). However, schools reported tight time limits and often daily situations got in the way of dedicating time to commit to the program.

Two public schools found Rethink to be an integral tool that had allowed them to track progress and determine when steps in a student's goal need to be changed to ensure success. A recent parent meeting allowed

for the TA to demonstrate how well one student had progressed since starting with Rethink. She used the program's data set on the child to evidence her feedback. These parents were surprised at how quickly their non-verbal child had mastered skills, and maintained those months later. This resulted in discussions between parents and another parent wishing to sign up for the program.

Another school teacher reported great benefit in using Rethink's task analysis to establish why a student was struggling with progress. Through assessment with Rethink, the goal was adjusted and the student was able to make progress and then achieve the end goal after a couple of weeks. Excitingly, although there was little formal program activity on the Rethink platform, many teachers and parents commented on printing off materials and lesson plans and then accessing the paper versions in class. Therefore there may have been more engagement offline than was recorded online.

Recommendations for any continued promotion of Rethink would be to host additional information sessions for prospective users, with guest speakers that currently use the program. This should be coordinated at the beginning of the year when new teachers have been allocated students, and with the assistance and coordination of DoE with the Rethink coach. Until the licences expire, ongoing support remains in place through scheduled training times; webinar meetings and travel as requested. Any new interest is welcomed and supported.

Learnings from the Rethink pilot include the need for better cross-agency collaboration between DoE and DHHS. Essentially Rethink was implemented within DoE under the auspices of DHHS. There are several evidence-based therapeutic modalities for people on the autism spectrum, including ABA and relationship

focussed interventions. The Panel recognises the merits of different styles of evidence-based interventions and the benefits of using a variety of modalities to meet individual needs. Rethink uses an ABA style of therapeutic input over a digital platform. DoE already has multiple supports for students on the autism spectrum including autism consultants, satellite classes and positive partnerships that at times do not align with an ABA style of therapeutic input and at times were hesitant to introduce another modality to their facilities. Following the pilot of the Rethink program, taking into account the limited uptake despite additional support and the transition to the NDIS the Panel recommend that the program is not bulk purchased by the state. If current users wish to continue to utilise the program, individual licenses are available for purchase through Rethink directly.

Social Attention and Communication Surveillance - Revised (SACS-R) Research

Currently, in Australia, and specifically Tasmania, the average age of diagnosis is four years, resulting in a window of missed intervention opportunity for many children⁵. Research shows that by enabling earlier access to intervention, via early identification and diagnosis, children have better cognitive outcomes with only few subsequently meeting criteria for an intellectual disability.

The SACS-R training in Tasmania (2017) was well received and attracted 201 professionals from across the state including CHaPS, allied health professionals, diagnosticians, paediatricians and early childhood intervention staff.

Since January 2017, SACS-R has been used by CHaPS for children at 12 and 24 months

of age during the child's universal health screen. In the southern region, SACS-R is also being used at a newly re-instated 18 month check. This check is also available in the north and north-west on request. Children with atypical results are offered referral for a full developmental assessment.

It is anticipated that the implementation of the SACS-R and follow-up of referrals will result in the early and accurate diagnosis of at least half of children on the autism spectrum before two years of age and at least 70 per cent by three years of age.

Victoria is further along in its implementation journey and has successfully reduced its age of diagnosis to 20 months within the SACS-R study, with the majority of children entering the study at their 18-month check.

Early identification and diagnosis will result in earlier access to relevant early intervention programs, therefore maximising developmental outcomes for affected children and their families. It will also decrease the stress that families often undergo during the frequently long and drawn out process to receive a diagnosis for their young child, due to lack of expert knowledge of the early signs.

The roll-out of SACS-R in Tasmania has resourcing implications for St Giles, the diagnostic service participating in the research. This involvement will see an increase in assessments required as participants undergo multiple assessments prior to their formal diagnostic assessment. The Tasmanian Autism Diagnostic Service (TADS) and St Giles are both funded by the DHHS (TADS is also part funded by the DoE) and are committed to supporting the project. The rollout also has implications for public and private paediatricians and early intervention services as it is expected that referrals to all of these services will commence from an earlier age and increase

⁵ Taylor, L., Brown, P., Eapen, V., Midford, S., Paynter, J., Quarmby, L., Smith, T., Maybery, M., Williams, K. & Whitehouse, A. (2016) *Autism Spectrum Disorders Diagnosis in Australia: Are we meeting Best Practice Standards?* Autism Co-operative Research Centre, Brisbane.

in quantum. However, this may be offset by children requiring less intervention later on as they obtain the benefits of very early intervention.

Additional funding has been provided to St Giles to cater for the increased number of referrals for early diagnostic services. St Giles has been provided with funding for an additional 0.8 FTE worker to provide assessments statewide for the estimated increase of approximately 100 assessments that are anticipated as a result of the SACS–R project. Early and accurate diagnosis will reduce the strain on diagnostic services when children are older (and potentially attending several diagnostic centres) and reduce the pressure on publicly funded early intervention services, as these children once diagnosed are eligible for alternative funding packages.

The success of the project will require cooperation from a number of research partners, including the Autism CRC, UTAS, St Giles, Latrobe University, and DHHS, all of which are already in support and in discussions regarding the implementation.

In addition, a free smartphone application that could help parents detect autistic traits in their very young children has been recently developed by the Latrobe Olga Tennison Autism Research Centre. This has recently attracted media attention. If parents begin to use the application, this could result in them asking autism-related questions of the CHaPS nurses, or requesting assessments at a younger age. The development of this app is an extension on the work and findings achieved through SACS–R research in Victoria.

The implementation of early surveillance through the use of SACS–R represents the beginning of a suite of work within this field that DHHS may now be in a better position to continue to be involved in.

The funding for the SACS–R pilot for additional diagnostic services and the reintroduction of the 18-month check in the state's south is being met through the autism election commitment. DHHS will also contribute over \$800 000 in cash and in-kind services over the four and a half years of the partnership agreement with the Autism CRC, the lead agency of the SACS–R project.

The Autism CRC has allocated \$79 866 to the SACS–R study for a PhD scholarship that will be supported through UTAS along with a research assistant position. It has also provided funding for a testing kit, test forms and travel for the PhD student to travel to Latrobe University for support from the research developers. The research assistant will also be managed locally at UTAS to undertake many of the administrative tasks of following up potential referrals of families through SACS–R. UTAS will be providing in kind local project management through a Memorandum of Understanding with the Autism CRC.

Disability and Community Services has committed an annual funding amount of \$99 960 (total \$199 920 for two years) to CHaPS to employ an additional 1.2 FTE Registered Nurse Grade 3-4 to reinstate the 18-month child health assessment in the south for the duration of the project.

ToR 2: Assessing viability and benefits of clinics for assessment and treatment

At a Glance

Background

Historically, assessment and intervention services have been state funded services in Australia, typically located within health or disability jurisdictions. Services for people on the autism spectrum were funded by all tiers of government and delivered under the umbrella of services for people with disability.

With the rollout of NDIS across Australia, diagnostic and assessment services will remain a state funded responsibility, while some intervention and therapy services for individuals will be funded by the NDIS.

There are few government funded services that are designed exclusively for people on the autism spectrum unless research-funded; the major exception to this being the Australian Government's Helping Children with Autism (HCWA) program, which is being phased out following the rollout of NDIS.

Some limited mainstream health services accessed by people on the autism spectrum attract Medicare rebates. In addition, people on the autism spectrum access mainstream services offered to the broader community, such as hospitals, health care, mental health services, schools and social housing.

In September 2017, the Autism CRC released a draft version of proposed national diagnostic guidelines in an effort to encourage Australian diagnostic assessment services to aim to provide services that are meeting best practice standards.

Tasmanian Context

Tasmania currently provides mainstream allied health services, mental health services, disability specialist services, Early Childhood Intervention Service (ECIS) and support within schools. These services are accessible to the broader community including people on the autism spectrum. There are also two autism specific services available in Tasmania – the state funded, statewide Tasmanian Autism Diagnostic Service (TADS) and the Commonwealth Government funded Autism Specific Early Learning and Care Centre (ASELCC) based in the north-west. DoE also funds autism consultant positions to assist in accommodating the needs of students on the autism spectrum within educational settings.

Diagnostic assessment services can be accessed through state-funded services – namely TADS or the Developmental Assessment Team at St Giles or through private providers (potentially attracting a Medicare rebate). There has been a substantial increase in waiting times for publicly funded assessment services from referral to assessment time with typical waits being around 12 months. The average age of diagnosis of autism in Tasmania is approximately four years of age. The Panel has endorsed and supported participation in a statewide research trial for SACS-R aimed at improved early detection and diagnosis of ASD.

The transition to NDIS has also changed the landscape of service delivery for Tasmanians on the autism spectrum. The NDIS will fund disability supports that are reasonable and necessary i.e. related to a person's disability and required for them to live an 'ordinary life'. As full-scheme NDIS is rolled out across the state there will remain a need for accessible mainstream services to deliver non-disability services.

Recommendations

- 2.1 Support from state government to implement *The diagnostic process for children, adolescents and adults referred for assessment of autism spectrum disorder in Australia: National guideline*.
- 2.2 Provide incentive and opportunities for allied health staff with skills, experience and desire to work in the field of autism diagnosis within Tasmania by providing bonded scholarships for professional development for clinicians to attend training for the Graduate Certificate in Autism Diagnosis in Western Australia or similar.
- 2.3 Initiate best practice standards and aim for a wait time from referral to assessment service to commencing assessment of no longer than three months.
- 2.4 Establish a state funded adult autism assessment service for people aged over 18 years.
- 2.5 The Tasmanian Government use its position on the COAG Health Council to urge the Australian Health Ministers' Advisory Council (AHMAC) and the Commonwealth Department of Human Services to remove the age cap for the Medicare rebate for the diagnosis and assessment of ASD.

The Transition to NDIS

The transition to NDIS will have a fairly significant influence on services in Tasmania.

Currently there are state funded autism assessment and diagnostic services for people under 18 through the Tasmanian Autism Diagnostic Service (TADS; statewide mobile clinics; 0-18 years) and the Developmental Assessment Team at St Giles (north and south; 0-5 years). State funded intervention services are available at present through St Giles in the south and north of Tasmania, Tasmanian Health Service and Child Development Unit in the north-west, and statewide services through the Early Childhood Intervention Service (ECIS) and some psychology and speech pathology services through schools. There currently are no publicly funded specialist assessment or intervention services for adults on the autism spectrum in Tasmania.

By 30 June 2019, NDIS funded services will have replaced some of the intervention services for people deemed eligible to be NDIS participants. NDIS can support people to access reasonable and necessary supports to pursue their goals, objectives and aspirations, increase their

independence, increase social and economic participation and develop their capacity to actively take part in the community.

NDIS also has a national approach to Early Childhood Early Intervention (ECEI) that gives children aged 0–6 years quick access to support tailored to their needs. This support might be information, emotional support or referral to other services like community health services, playgroups or peer support groups. A child may also receive therapy sessions with Early Childhood Early Intervention providers in the short term or medium term. A child may need an individualised NDIS support plan if they have longer term support needs.

Children are still able to access HCWA funding and publicly funded therapy services until they transition to the NDIS. In addition to the HCWA package, the Australian Government has established six Autism Specific Early Learning and Care Centres (ASELCC) to provide early learning programs and specific support for children aged 0-6 years on the autism spectrum in a long day care setting. There is an ASELCC located in Burnie, on the north-west coast.

State-funded services continue to be available for children on the autism spectrum via Children's Therapy Services. These services are available via St Giles in the north and south of the state and via the North West Regional Hospital in the north-west. Typically they provide more intensive services for children under school age (5 years). Education support is also offered through ECIS. It is interesting to note that under the existing state funded system, services seem to become more difficult to access around the age of 5 years, which is shortly after the average age of diagnosis (4 years). Existing services also tend to be provided based on school terms, despite children's needs existing year round.

DoE also provides in-school support through autism consultants and autism specific classes located in Lindisfarne North Primary School, Rose Bay High School, Summerdale Primary School and Romaine Park Primary School.

Autism Assessment Services in Tasmania

Typically, both TADS and St Giles have considerable waiting lists for assessments. Some public health paediatricians offer diagnostic assessment of ASD, however they still have a considerable waiting list. There are also some limited user-pays services throughout the state from private practice paediatricians and psychologists. Some Tasmanian residents have also flown to Melbourne to access diagnostic services.

TADS offer a statewide service for children aged 0–18 years. Jointly funded by DHHS and DoE, TADS provides assessment based on direct input from a psychologist and input from other treating clinicians and medical professionals. In December 2017, there was about an 11-month wait from time of referral to assessment. St Giles is also funded to provide a diagnostic service in the north and south of the state for

children aged 0–5 years. It is able to provide a multidisciplinary assessment including psychologists, speech pathologists and occupational therapists. Typically there is a 6 to 12 month wait time for this service.

TADS provide an assessment only service for people across Tasmania under 18 years of age. The service is based in Hobart and also travels around the state conducting regular assessment clinics in various locations. Referrals are accepted from a paediatrician, child/adolescent psychiatrist or psychologist. This two-step referral process can add an additional 4–6 months to the wait for assessment. TADS assessments focus solely on whether or not a person has ASD. They do not provide a more general picture of the child's development or consider comorbid or alternative diagnosis. They do provide a detailed picture of the child's diagnostic profile. Currently, the assessing team from TADS consist solely of psychologists, and assessments are conducted in one day in a clinic setting. It does however draw on information from other professionals and people familiar with the child as part of the assessment. Following assessment, TADS provides a feedback session to discuss the outcome of the assessment and intervention and treatment suggestions are discussed. TADS is also able to recommend referrals to other services.

St Giles currently provides children's therapy services in the north and south under a DHHS funding agreement. As a part of this agreement it has established a Developmental Assessment Team (DAT) to provide developmental assessments for children under 5 years of age. St Giles requires a referral from an early intervention provider, allied health or medical professional for assessment by DAT. Assessments from DAT do consider broader developmental profiling. DAT consists of professionals from psychology,

speech pathology and occupational therapy. DAT frequently sees children across contexts, e.g. childcare settings and draws on information from other professionals and people familiar with the child, e.g. paediatricians. The service offers cognitive/developmental assessments, multi-disciplinary diagnostic assessments and Autism Spectrum Disorder diagnostic assessments. St Giles is able to provide intervention services under its publicly funded contract or through its private fee for service arrangement.

Some people choose to use private psychologists and paediatricians to obtain a diagnosis. There are some Medicare items available to fund assessment, diagnosis and the creation of a treatment and management plan by a consultant paediatrician or a psychiatrist for a child under 13 years of age. The paediatrician or psychiatrist is then able to refer a child to an eligible allied health provider to assist with diagnosis of the child or for the purposes of contributing to a treatment plan. Medicare rebates are available for up to four diagnostic/assessment services from psychologists, speech pathologists, occupational therapists, audiologists, optometrists, orthoptists, or physiotherapists to assist the referring practitioner with diagnosis or contribute to a child's treatment and management plan (for a child under 13 years of age). It should be noted that these rebates only cover a portion of fees charged by practitioners and most consultations will attract an out of pocket fee.

There are currently no state funded assessment and diagnostic services for people over 18 years of age. To obtain a diagnosis, people must seek out

private services from suitably qualified diagnosticians. There is no additional funding or Medicare rebate available for these services.

Process of Diagnostic Assessment

Diagnosis of ASD has historically been a complicated and challenging task. There is no single test for ASD and no diagnostic test which provides 'a definitive answer'. Assessment is centred on clinical judgement based on behavioural observation.

However, there is great variability in ASD symptoms and the considerable behavioural overlap with other developmental conditions means that ASD diagnosis is not a straightforward clinical task.

There is considerable variation between the states and territories over the composition of clinical assessment teams and minimum diagnostic requirements. Some states require an ASD diagnosis to be made through a multi-disciplinary team, other states have other criteria. Different diagnostic standards can also apply between health, education and disability public services offered by each state/territory and federally, such that a diagnostic decision that is recognised by health or disability services early in life, may not be recognised by the education system when the child reaches school age. Waiting lists for assessment in Tasmania are currently the second longest in Australia⁶. Current clinical guidelines recommend that ASD diagnostic assessments start within three months of referral to an autism team⁷. Long waitlists may impede access to early intervention and lower parental satisfaction with diagnostic processes.

⁶ Taylor, L., Brown, P., Eapen, V., Midford, S., Paynter, J., Quarmby, L., Smith, T., Maybery, M., Williams, K & Whitehouse, A. (2016) *Autism Spectrum Disorders Diagnosis in Australia: Are we meeting Best Practice Standards?* Autism Co-operative Research Centre, Brisbane.

⁷ NICE. (2011). *Autism in under 19s: recognition, referral and diagnosis*. Retrieved from <https://www.nice.org.uk/guidance/cg128>

The Autism CRC released a draft national guideline for assessment of autism in Australia in September 2017 with the intention to provide an evidence based, step by step process for conducting an ASD assessment from the time of referral until the assessment results are shared in a written report⁸.

Since its inception, the Panel has explored diagnostic assessment processes in other jurisdictions alongside evidence based, best practice models. The Panel has also invited various Tasmanian public and private diagnosticians to provide an overview of their processes. It has been identified that there is a need for a multidisciplinary team that can provide diagnostic assessment services for autism spectrum disorders; differential diagnoses and co-morbidities associated with or in addition to this disorder at the same time, in the same place, minimising the need for families to have to visit multiple services, which is inefficient, stressful and costly.

Currently there are long waiting times in Tasmania to see a public health paediatrician. This impacts on timeliness of referrals to both diagnostic and early intervention services. There are limited state funded diagnostic services in the north-west and often families are required to travel to the north or south, which places additional pressure on these families, particularly those living in rural and remote areas.

DHHS funds St Giles to deliver assessment and diagnostic services to children 0–5 years in the north and south. This service is often very full and frequently closes its books to new referrals later in the year to children approaching kinder entry. DHHS and DoE jointly fund TADS to provide assessment and diagnostic services across the state, including the provision of outreach clinics in

rural and remote settings. This service is also at full capacity.

It seems that the provisions of diagnostic services across the state are inequitable and often not able to provide timely, affordable and consistent diagnoses for autism spectrum disorder to the community.

To meet current best practice standards across the state and the community, Tasmania requires:

- a consistent and equitable state-wide approach for assessment and diagnosis of ASD
- a multi-disciplinary team assessment
- accessibility to all health regions of the state.

Lowering the Age of Diagnosis

Tasmania is currently participating in the SACS–R project with the aim of recognising traits of autism earlier, thereby attempting to lower the average age at diagnosis.

Lived Experience of Assessment Processes in Tasmania

A recent consultancy⁹ highlighted that participants found the process of obtaining a diagnosis drawn out and difficult. Many parents reported significant concerns with the lack of support received post-diagnosis and being unaware of the next steps required to access intervention services. The report from Banks Spencer recommended the government '*Undertake an urgent review of services that are available immediately post-diagnosis for parents to identify opportunities for improved access to psycho-social support and guidance on how to navigate the system*'.

⁸Whitehouse AJO, Evans K, Eapen V, Prior M, Wray J. (2017) *The diagnostic process for children, adolescents and adults referred for assessment of autism spectrum disorder in Australia: A national guideline* (Draft version for community consultation). Autism CRC Ltd, Brisbane

⁹Spencer, A. (September, 2017) *Being on the Autism Spectrum – understanding the journey in Tasmania*. Report to the Autism Advisory Panel and Tasmanian Government Department of Health and Human Services

Furthermore, it also noted that the process of obtaining a diagnosis as an adult can be a lifelong journey and is contingent on happening across a specialist who is experienced in the presentation of autism in adults. In Tasmania, there are no government funded services able to provide an assessment service for adults. The report recommends that the government facilitate an expansion of autism diagnostic services to include all ages.

Learning from Other States

Within the report from the Victorian parliamentary inquiry it is noted that referral and support should take place as soon as there is concern about a child's behaviour and development. Victoria, similarly to Tasmania, has a number of referral pathways, which makes it confusing for parents and professionals alike. These referral pathways include primary health practitioners such as GPs, child health nurses, early childhood intervention services, community health services and allied health practitioners. The report makes recommendations to increase awareness, understanding and clinical assessment skills to these primary referrers, namely child health nurses and GPs.

The inquiry also recognised current best practice in ASD diagnosis to be a multidisciplinary diagnosis involving at a minimum, a paediatrician or child and adolescent psychiatrist, a psychologist and a speech pathologist. This is consistent with key international and national guidelines on the assessment of ASD.

An additional recommendation stated in this report is for the Victorian Government to introduce a model of best practice in ASD diagnosis, which consists of a multidisciplinary diagnosis involving at a minimum, a paediatrician or child and adolescent psychiatrist, a psychologist and a speech pathologist to be provided by the state's public health system. Additionally the report set a target for assessment to be conducted within three months of a referral.

Similarly to Tasmania, Victoria currently has no publicly funded adult ASD assessment clinics. In order to obtain a diagnosis, adults have to see private psychologists and psychiatrists, which can come at a high cost. The Victorian inquiry recommended the government use its position on the COAG Health Council to urge the Australian Health Ministers' Advisory Council (AHMAC) and the Commonwealth Department of Human Services to remove the age cap for the Medicare rebate for the diagnosis and assessment of ASD. It further recommended that specific provisions are made to improve services for adults, including access to public ASD diagnostic assessment teams. Another recommendation that came from the inquiry was that the Victorian Government collaborates with relevant professional and training bodies to ensure training is provided to health professionals in identifying the traits and presentations associated with ASD in adults and to develop training programs for health professionals in the assessment and diagnosis of ASD in adults. An adult specific diagnostic assessment service in Tasmania is also recommended.

ToR 3: Consider professional development of mainstream front-line workers and other professionals

At a Glance

Background

There are many barriers to people on the autism spectrum accessing mainstream health and mental health services, including a lack of understanding of ASD by health practitioners, and communication difficulties and sensory sensitivities. Health professionals also reported that communication difficulties, challenging behaviours, diagnostic overshadowing and the heterogeneity within ASD made it difficult to diagnose and treat health and mental health conditions.

People accessing mainstream health and mental health services reported confusion, a lack of co-ordination between health professionals working with the same individual, and a lack of understanding about ASD across the health and mental health system. Some parents of children with ASD reported difficulties ensuring that their children had access to mainstream health and dental services due to their heightened anxiety and sensory needs.

Tasmanian Context

The Tasmanian State Government through its *Disability Framework for Action (DFA)* has committed to improving state service employees' access to disability specific awareness training and building the capacity of health and community services in relation to working with people with behaviours of concern.

Tasmanian fire, police and ambulance services all report access to training on working with vulnerable people including working with people on the autism spectrum and communication difficulties.

There are several options available for professional development for teachers in Tasmania, including Rethink Autism and Positive Partnerships. The Autism CRC has specific resources readily available to assist health workers supporting people on the autism spectrum.

Recommendations

- 3.1 Establish a training program for new teachers, nurses, medical practitioners, allied health and paramedic workers to access autism specific training.
- 3.2 Development of an online training program/ information campaign for all front-line workers and professionals to include the private sector and community/disability workers.

Disability Framework for Action

The *Disability Framework for Action 2013–2017* specifies an area of action under inclusive and accessible communities to ‘undertake disability awareness training for state service employees including senior management’ alongside ‘building capacity in health and community services in relation to working with people with challenging behaviours’. Outcome area six of the framework also aims to ‘ensure all health service providers are responsive to the needs of people with a disability’ and ‘ensure a strong interface between disability services and Tasmanian Health Organisations including hospitals and primary health services to respond to the needs of people with disability in Tasmania and provide comprehensive accessible and flexible services’. This framework demonstrates the current state government’s commitment to considering the professional development of state service employees including front-line workers and can assist in providing the Panel with a conduit for promoting autism specific training and resources.

Currently Available Professional Development and Resources

Emergency services were contacted by representatives of the Panel in order to establish a preliminary needs analysis for training and professional development. This enquiry sought to collect information about what is currently occurring and existing training gaps in terms of front-line workers interacting with people with autism. Police, ambulance and fire departments all report providing staff training on working with ‘vulnerable people’, including people on the autism spectrum. Tasmania Police in particular report that they are trained to respond to people as though they are

vulnerable until proven otherwise. It was made evident that these services have very full training schedules at present. All services nominated that a digital, self-paced platform would be the most accessible way for their staff to gain additional training in autism.

DoE staff have access to a variety of training and professional development in relation to autism. Positive Partnerships is a national project funded by the Australian Government Department of Education and Training through the Helping Children with Autism (HCWA) package. This is delivered by Autism Spectrum Australia (Aspect), with a goal to improve the educational outcomes of school-aged students on the autism spectrum. It works with schools, communities and families across Australia to deliver evidence based content through workshops, webinars and online learning through its website. Positive Partnerships provides a range of programs and resources to assist teachers, school leaders and other education professionals to support students on the autism spectrum in the classroom and other school contexts, and create an ‘autism friendly’ school culture. While a range of programs is offered via Positive Partnerships according to data provided by Aspect¹⁰, there seems to be a fairly limited uptake by schools. The data indicates over a 4-year period of Positive Partnerships providing training that only 25 percent of schools accessed it (that is 70 out of a possible 283 schools). Further, from 2012–2015 inclusive, a total of 126 teacher participants attended either the five-day or flexible professional development program, indicating a fairly low uptake of the program.

The implementation of Rethink Autism has also provided resources and professional development opportunities for teachers and other education staff. Teachers have consistently reported to the Rethink Coach the value of the resources; it is also one of the most accessed parts of the program.

¹⁰ Email correspondence from Lee Casuscelli

The final report provided by Banks Spencer from the statewide forums to discuss the lived experience of autism in Tasmania makes the recommendation that “*The Tasmanian Government Departments of Education and Health and Human Services commit to work collaboratively to develop and implement minimum autism awareness and inclusion training requirements that all schools must demonstrate having achieved*”.

Autism CRC

One of the Autism CRC’s programs is improving health and wellbeing for autistic adults. As part of this program they have developed a Health Hub with the intention of providing autistic adults, their carers and families, and health professionals with up-to-date health and wellbeing resources emanating from research undertaken by Autism CRC researchers. There is a range of health and mental health resources for people with ASD and medical professionals on the Health Hub website, including information on how medical professionals should communicate with people with ASD, as well as visual boards to convey medical procedures and instructions. Guidance for health professionals includes:

- showing empathy and understanding of the sensory, communication and processing differences
- providing visual information
- giving the individual time to process verbal information in order to be able to respond
- providing a quiet environment
- understanding the communication preferences and needs of the individual.

Learning from Interstate

The Victorian inquiry into services for people on the autism spectrum recognised that health professionals in public hospitals and healthcare facilities need to be trained in recognising and understanding ASD¹¹. Public health professionals need to have the knowledge and skills to be able to manage communication difficulties, sensory sensitivities and behavioural concerns without resorting to restrictive practices. In response to the parliamentary inquiry, the Victorian Government has committed to developing a workforce that is educated and trained to meet the diverse needs of people on the autism spectrum. To do this they are developing a strategy for building ASD competency across mainstream workforces – that is health, mental health, education, justice and public transport and community support to better equip them to respond positively to people on the autism spectrum¹².

¹¹ Family and Community Development Committee of the Victorian Parliament (June, 2017) *Parliamentary Inquiry into services for people with Autism Spectrum Disorder final report*

¹² Victorian Government (December, 2017) *Response to the parliamentary inquiry into services for people with Autism Spectrum Disorder*

ToR 4: Delivering awareness, education and practical help

At a Glance

Background

Recent research is indicating that it is important to build not just awareness but also *understanding* in order to shift public perceptions of ASD and thereby increase access to community and public arenas and events. Figures from the United Kingdom show that whilst 92% of people have heard of autism, and most seem to understand it is a disability, challenges still exist in promoting understanding of the condition. There are widespread misconceptions about the exact characteristics of autism, how common it is and who is affected by it. There are also many negative reactions to the typical behaviours commonly associated with autism and the impact that these have on those living with the condition, including family and friends. People on the autism spectrum and their families have frequently been isolated, marginalised and have felt excluded. This has stemmed from the core challenges that people on the autism spectrum face in terms of communication, socialisation and their sensory issues – as well as the institutional challenges of including people on the autism spectrum across all settings. The social costs of failing to include people on the autism spectrum in the community have contributed to a loss of health and wellbeing for these people and their families.

Tasmanian Context

The Tasmanian DFA commits the state government to increasing awareness of disability and improving accessibility to people with disability in Tasmania. The Panel has the opportunity to utilise this platform to initiate an autism specific awareness campaign and generate autism specific resources. People on the autism spectrum and their families have reported their desires for 'autism friendly' venues and activities and a more socially inclusive community.

Recommendations

- 4.1 Develop a public awareness campaign to inform the Tasmanian community about people on the autism spectrum and their needs.
- 4.2 Develop an endorsed 'autism friendly' accreditation for businesses and services to assist in promoting positive images of people on the autism spectrum and combatting community ignorance.

Tasmanian Government Policy and Action plans

The state government has already set out various policies and frameworks for action to provide awareness, education and practical support for people with disability and their families.

The Tasmanian State Government sets out in its DFA that it will:

- promote awareness and acceptance of the rights of people with disability
- meaningfully engage people with disability in the design of policy and legislation.
- increase opportunities for and participation of people with disability in community, cultural, sporting, recreational and physical activity
- acknowledge and support the role of families and carers.

Additionally, the Tasmanian Carer Policy aims to *'recognise the commitment of Tasmanian carers and support them in their caring role as well as supporting active participation in economic, social and community life for themselves and the people for whom they care'*. More specifically, one of the underpinning policies states *'government agencies are to be given appropriate support to understand and respond to the needs of carers'*.

These provide a platform for the Panel to recommend more autism specific supports to effect change on a whole of government level.

The Lived Experience of Tasmanians with Autism

The forums commissioned by the Panel to gain insight from Tasmanians on the autism spectrum about their lived experience in gaining a diagnosis, accessing services and engaging with the community, provided insight into the current struggle of Tasmanians on the autism spectrum accessing mainstream services¹³.

The report highlighted that some parents and participants with autism alike avoided anything that may require social interaction, avoided involvement or chose a time that minimised contact, thus meaning that the use of mainstream services was difficult at times. Parents were concerned about being judged and people on the autism spectrum were keen to avoid small talk if at all possible.

A common theme raised by participants was the desire for services to be listed as 'autism friendly', be it a school, GP, or medical specialist. It is acknowledged that what constitutes 'autism friendly' may be difficult to establish, and potentially create barriers that prevent cohesion, cross sector collaboration and cooperation within and between the education, health and community sectors.

Education and/or training that bridges gaps in understanding, as well as power imbalances between parents, teachers, clinicians and other service providers, and work towards a socially inclusive community, would benefit from being targeted at all stakeholders, including those delivering and receiving services. Parents and people on the autism spectrum could be better supported through provision of training that empowers them to advocate on their own behalf.

¹³ Spencer, A. (September, 2017) Being on the Autism Spectrum – understanding the journey in Tasmania. Report to the Autism Advisory Panel and Tasmanian Government Department of Health and Human Services

It should also be noted that many parents of people on the autism spectrum have developed a wealth of knowledge and understanding of ASD and the effects it has on daily life.

This presents an opportunity to develop their skills and confidence as experts on ASD to assist not only themselves, but others in Tasmania.

Learning from Other States and Overseas

In the *Parliamentary Inquiry into services for people with Autism Spectrum Disorder final report*¹⁴ a recommendation is put forth to ensure that all new and existing public hospitals and healthcare facilities have provision for dedicated quiet spaces for people with ASD in emergency departments and other inpatient and outpatient areas.

The Victorian inquiry further outlined the poor co-ordination and collaboration between different services. For people with ASD and a co-occurring mental health condition, a lack of knowledge of ASD by health professionals and an absence of sector collaboration within mental health services were detrimental to their health and wellbeing.

In response to the parliamentary inquiry, the Victorian Government has committed to developing a public education campaign to assist in informing the general community, including front-line workers about people on the autism spectrum and their needs¹⁵.

Aspect, Australia's largest service provider for people on the autism spectrum has commenced a program in an effort to make community spaces and services more autism friendly. At present it is a fee for service arrangement that involves a site visit with a professional and a representative from the autistic community to assess environmental factors that could be challenging to visitors on the autism spectrum. Autism SA, a not for profit organisation supporting people in South Australia is also currently running an 'Autism Friendly Initiative' funded by NDIS through their Information, Linkages and Capacity building (ILC) funding.

In the UK, the National Autistic Society (NAS) commenced a national awareness and understanding campaign in 2016. Its research demonstrated that many people had heard of the term autism, but very few actually understood the implications of diagnosis. Further, its statistics showed that 28 percent of people on the autism spectrum had been asked to leave a public space because of behaviour associated with their autism and 79 percent of people on the autism spectrum felt socially isolated. The campaign "Too Much Information" was designed to assist the general community to understand that being on the autism spectrum means having a brain that is wired differently and can make someone see, hear and feel the world in a different way to other people¹⁶.

¹⁴ Family and Community Development Committee of the Victorian Parliament (June, 2017) *Parliamentary Inquiry into services for people with Autism Spectrum Disorder final report*

¹⁵ Victorian Government (December, 2017) *Response to the parliamentary inquiry into services for people with Autism Spectrum Disorder*

¹⁶ <http://www.autism.org.uk/get-involved/tmi/about/report.aspx>



ToR 5: Input from relevant organisations, professionals, families and carers

At a Glance

Background

Every person on the autism spectrum is unique, with different needs and goals for the future. It is important to take into account everyone's variable needs, supports, services and requirements when considering the landscape of living on the autism spectrum.

Tasmanian Context

In Tasmania, autism is the second most prevalent disability following intellectual impairment. We have many people and families living on the autism spectrum. There is a diverse range of services, organisations and professionals working alongside people living on the autism spectrum. Each person and organisation who has experience living with autism is able to provide a unique insight and contribution regarding the challenges faced and the possible ways forward.

Recommendations

5.1 The Tasmanian Government establish an advisory panel for consultation into the future consisting primarily of people on the autism spectrum and their families to help guide and steer the future development of policies, services and supports that affect them.

Autism Advisory Panel

The Panel represents a diverse cohort including people on the autism spectrum, family members of people on the autism spectrum, service providers and peak body organisation representatives. To complement this range of membership, guest speakers have frequently been invited to attend Panel meetings to provide feedback and insight into alternate aspects of the lived experience of autism in Tasmania. The Panel, through its professional, community and personal networks has had the opportunity to gain insight from a wider pool of people within the Tasmanian ASD community.

Over its four-year term, the Panel has invited the director of TADS, private allied health providers, paediatricians, NDIS ECEI providers, Autism CRC representatives, and Rethink Autism representatives to contribute to its work.

Over the years, as Panel members have resigned, taken leave or decreased their participation, there has been a perceived loss of balance of input and insights from important sources. Looking to the future, if a representative Panel continues to exist, it is suggested that as representatives from specific cohorts e.g. parent representatives step down, that they are replaced by other representatives from the same/similar cohorts within a short timeframe.

The Lived Experience of Tasmanians with Autism

The Panel contracted Banks Spencer Consulting to undertake a series of focus groups around Tasmania to learn from people on the autism spectrum and parents/carers of their experiences in gaining a diagnosis, accessing services and engaging with the community.

A total of five focus groups were held in Burnie, Launceston and Hobart, with 13 people attending. While participants recounted different lived experiences, there were some consistent themes that emerged about grief at the time of diagnosis, difficulties accessing services and the need for identified 'autism friendly' services. Despite the low participation rates, the themes that emerged from the forums are similar to other bodies of work from interstate and are likely to still be relevant.

A total of eight recommendations came from the forums, including regular surveys to collect quantitative data regarding service uptake, provision of post-diagnosis support, expansion of diagnostic services to include people over 18 years and access to self-advocacy opportunities.

ToR 6: Whole of Government strategy

At a Glance

Background

The ASD policy landscape, both federally and in Tasmania, needs reform to better reflect the needs of people on the autism spectrum, more recent understandings of ASD, and the emergence of ASD as a condition that affects significant numbers of Australians and their families.

Tasmanian Context

As at 30 September 2017 there were 2 915 participants in the NDIS, including Early Childhood Early Intervention (ECEI) approach participants. Thirty-six per cent of those participants identify as having a primary diagnosis of autism in Tasmania. The 2015-16 National Minimum Data Set (NMDS) reports less than seven per cent of people accessing specialist disability services had a primary diagnosis of autism. The NDIS data may demonstrate a higher rate because of the age profile of participants currently.

The *Disability Services Act 2011* includes a requirement for a three year strategic plan to be approved by the Minister and to set out the outcomes intended to be achieved in the State. Both the *Disability Services Act 2011* and the *Disability Services Strategic Plan* are currently under review.

Tasmania's DFA and the *Tasmanian Carer Policy and Action Plan* both contain specific strategies that could complement and assist the success of a Tasmanian autism specific strategy.

Recommendations

- 6.1. Undertake a desktop review of the available data relating to participants on the autism spectrum in the NDIS and the outcomes they are achieving, including the outcomes in mainstream services.
- 6.2. Establish ongoing biannual targeted interviews with people on the autism spectrum and their parents/carers to assess the outcomes achieved, including access and inclusion in mainstream services.
- 6.3. Include an autism-specific focus in the *Disability Services Strategic Plan 2019–2021*.
- 6.4. Include autism specific actions to improve access to services and outcomes for people on the autism spectrum in the *Disability Framework for Action* and Department of Health and Human Services (DHHS) *Disability Strategic Plan*.
- 6.5. Include autism specific actions to improve access to services and outcomes for people on the autism spectrum, their families and carers in the *Tasmanian Carer Action Plan 2013–2018*.
- 6.6. Establish a government-wide acceptance of what constitutes a diagnosis of autism to reduce duplication and unnecessary assessments for people accessing services across various departments.
- 6.7. Establish a consultation group that meets at least quarterly to review Autism CRC research opportunities and projects to make recommendations to the state government about participation in these activities.

All governments are committed to a national approach to supporting people with disability to maximise their potential and participate as equal citizens in Australian society. *The National Disability Strategy 2010-2020* sets out a ten-year national plan for improving life for Australians with disability, their families and carers. The commonwealth, state and territory governments have developed this strategy in partnership under the auspices of the Council of Australian Governments (COAG). This strategy forms the basis from which the Tasmanian DFA has been developed.

Disability Services Act

The *Tasmanian Disability Services Act 2011* is currently undergoing review and the Disability Services Strategic Plan and DFA will be reviewed shortly. This presents an opportunity for autism specific elements to be included in future planning for the State.

Tasmanian Carers Policy and Action Plan

The *Tasmanian Carers Action Plan* is currently undergoing review and has the potential to complement a whole of government autism strategy by including autism specific components.

Service Mapping

During the early stages of the Panel, considerable efforts were made to map both public and private services available in the state as well as complete a prevalence study. There were many inherent difficulties with this task and gaining quality results proved enormously challenging.

Overall, this exercise demonstrated gaps in diagnostic services in the north-west and the inability of private providers to fill the gaps as this was dependent on affordability for families and the skill and capacity of providers. There was a geographic concentration of services around Hobart.

Glossary

Early Intervention – Therapeutic intervention commenced as soon as practical following diagnosis regardless of age at time of diagnosis.

ABA – Applied Behaviour Analysis

AHMAC – Australian Health Ministers Advisory Council

ASELCC – Autism Specific Early Learning and Care Centre

Aspect – Autism Spectrum Australia -Australia's largest nonprofit autism-specific service provider

Autism CRC – Co-operative Research Centre for Living with Autism

CHaPS – Child Health and Parenting Service

COAG – Council of Australian Governments

Comorbidity – the presence of another disorder or condition, alongside a primary disorder such as Autism

DFA – Disability Framework for Action

DHHS – Department of Health and Human Services

DoE – Department of Education

ECEI – Early Childhood Early Intervention

ECIA – Early Childhood Intervention Australia

ECIS – Early Childhood Intervention Service

HCWA- Helping Children with Autism

ILC – Information, Linkages and Capacity Building – NDIS funding type with focus on community inclusion

Mainstream services – most people interact with a range of services throughout their lives – including schools, GPs, Centrelink etc. These services are designed for everyone, they are not specifically for people with disability.

NDIA – National Disability Insurance Agency

NDIS – National Disability Insurance Scheme

Neurotypical – a term widely used to describe people not on the autism spectrum.

NMDS – National Minimum Data Set

SACS–R – Social Attention and Communication Surveillance – Revised

TADS – Tasmanian Autism Diagnostic Service

ToR – Terms of Reference

Terms of Reference – Attachment I

Purpose

The purpose of the Autism Advisory Panel is to provide inputs to the development of a long term inclusive Autism strategy that meets the needs of Tasmanians across their lifespan.

Role and Function

1. Examining and recommending best practice early intervention models that support children with autism, their families and carers, including the practicalities of access to the new web-based *Rethink Autism* program to ensure maximum use by parents, guardians, teachers, teacher assistants, child care organisations and others who support the child.
2. Assessing the viability and benefits of clinics that assess, and treat, autism and the many co-morbidities of autism and working closely with established services such as epilepsy support services.
3. Considering the professional development of health personnel, emergency services, education workers and other professionals in relation to how to best interact with people living with autism, and how to provide for inclusive support services for this population, including the introduction of a protocol, such as Autism Speaks.
4. The best means of delivering awareness, education and practical help for families and carers.
5. Seeking input from relevant organisations, professionals, families and carers caring for people with autism (and individuals with autism themselves) in addressing the Terms of reference.
6. To develop a whole of government autism strategy for Tasmanian's living with Autism Spectrum Disorder from birth and throughout adulthood. This strategy will identify gaps, service system issues and recommendations to the Minister for future service delivery models whilst describing the interface with the National Disability Insurance Scheme in the transition to full-scheme in Tasmania.
7. To provide a final report to the Minister for Human Services outlining the above, and
8. Any other matters hereto seen as relevant.

Current Membership

Chair:	Ms Cassie Xintavelonis (le Fevre) (Clinical Psychologist)
Deputy Chair	Mr Terry Burke (Autism Tasmania)
Membership:	Ms Lisa Risby (Parent with ABA experience)
	Ms Bec Wiaczek (Parent)
	Mr Ian Wright (St Giles)
	Ms Coral Cole (National Disability Insurance Agency)
	Mr Tim Chugg (Giant Steps)
	Ms Rosalie Martin (Speech Pathology Tasmania)
	Ms Lyndsay Quarmby (Rural Clinical School-UTAS)
	Kathryn Fordyce (Autism Specific Early Learning & Care Centre, NW Tas)
	Rowena Wilkinson (Early Childhood Intervention Service)
	Lynne McDougall (Department of Education)
	Ms Geraldine Robertson (Autistic Advocate)
	Mr Paul Potter (Consumer Representative)
	Ms Ingrid Ganley (Director Disability and Community Services-DHHS)
	Paediatrician Representative
	Parent representative with current involvement with early childhood intervention services

In addition, the current panel may also consider the following organisational representation:

- Child Health and Parenting Service
- Paediatrician
- Medicare Local
- Autism CRC
- Occupational Therapist (St Giles)
- National Disability Insurance Agency National Expert

Representation from the above may be considered by the panel as a 'critical friend' to the panel on specific matters of importance.

In exceptional circumstances, a proxy may be nominated to represent an entity or an individual on an ad hoc basis. If this situation arises, the person requesting the proxy needs to provide a written request to the Chair at least 48 hours prior to the following Panel meeting for their endorsement, outlining the reason for nominating the proxy, and their perspective on what skills and experience the proxy could bring to the meeting on a one off basis.

Member Roles

The Autism Advisory Panel will consist of a Chairperson (appointed by the Minister for Human Services) and other permanent members. Expertise may be called upon to join the panel on a permanent or irregular basis as need arises and with agreement from the current membership. The Department of Health and Human Services will provide a member to participate as an ex officio member of the Panel.

1. Secretariat support provided by the Department of Health and Human Services (DHHS).

Contact – Dianna King

Telephone: 03 6166 3663

Email: dianna.king@dhhs.tas.gov.au

2. Meeting venue provided by DHHS.
3. Project/research support up to two days per week as required.

The Autism Advisory Panel will:

- Maintain a record of discussions at any meetings held.
- Develop a communique outlining broad key messages at the end of each meeting and load onto the public website.
- Report to the Minister on new information and issues discovered relevant to the development of the long term Autism strategy for Tasmania.
- Provide a short report at the conclusion of the final meeting for the Minister's information that addresses the key issues in the Terms of Reference suitable for public release.
- Communication to the Minister for Human Services in regard to the outcomes and outputs of the Autism Advisory Panel work will be conducted via the Secretariat.
- Public communication in regard to the outcomes and outputs of the Autism Advisory Panel work should be communicated via the Chair, with the express consent of the Minister for Human Services.
- Member may appoint a proxy to attend Autism Advisory Panel meetings with the consent of the Chair.

Meeting Times

In recognition of the volunteer nature of the Autism Advisory Panel it is anticipated that the Panel will need to meet as required to sufficiently address the Terms of Reference.

The Panel should operate for as long as required to address the work before it. It is expected that this would be for at least one year. At that point, it would be expected that the Panel would hand down a report with a series of recommendations that may or may not recommend a continued role for such a leadership group into the future.