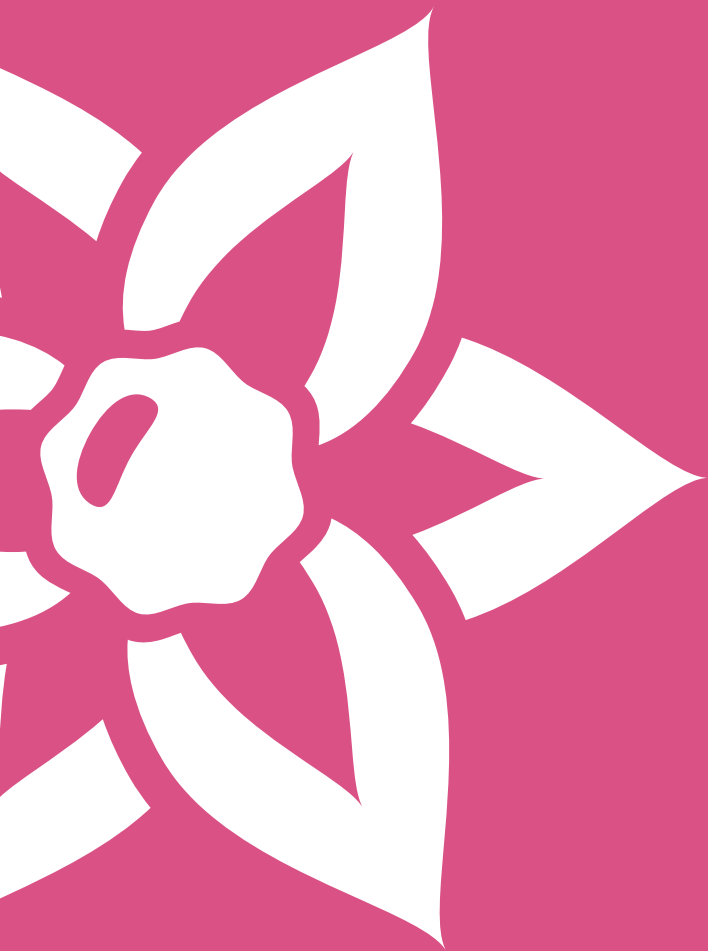


# **Autism in Tasmania:** State of the State 2023

**A systems view of the array of local, state and national programs and policies, that influence the life outcomes for Autistic Tasmanians.**

***“Informing the Reforms”***



***“The autism services “system” is currently delivered by every level of government, NGO’s, businesses and the wider community. It’s a confusing and poorly integrated approach to policy and program delivery... Right now every part of the system is being reviewed and reformed.”***

***- Skie Mitchell, Chairperson***

## **Acknowledgements**

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# Overview

## **Tasmania has a large and diverse Autistic community.**

*We come from every part of society, rich or poor, and from all cultural, language and religious backgrounds. Autism doesn't just express itself the same in everyone.*

*Autism is often not obvious especially in females and older people who have learned to adapt their behaviour. Not being able to speak does not mean that you have nothing to say.*

- Autism Tasmania Community Members

Autism touches the lives of many Tasmanians, from all backgrounds. It is estimated that between 2-3% of Tasmanians are Autistic (somewhere between 11,400 – 17,100 people).<sup>1</sup>

Nearly every Tasmanian knows someone who is Autistic, and around one in four people have an Autistic family member.<sup>2</sup> There are some very prominent Autistic Tasmanians.

Autism frequently runs in the family with multiple siblings, or parent and child being Autistic. Most Autistic people have other co-occurring conditions: ADHD, mental health, eating disorders, dyslexia, intellectual disabilities and epilepsy are common. Some Autistic people don't speak or only speak in some settings or circumstances. Autism is often an 'invisible' condition that may not be immediately obvious in the ways that many physical disabilities are.

## **Autistic people want to contribute to all aspects of Tasmanian life.**

Despite facing challenges, the Tasmanian Autistic community is filled with skills and talent and people who want to play an active role in all aspects of Tasmanian life.

Autistic people overwhelmingly want to study, work, volunteer, create, sustain friendships, have families, be involved in their community and live good lives. If harnessed, the considerable untapped skills and talent of the Autistic community can make a significant contribution to Tasmania's economic and community life.

## **As a group, Autistic Tasmanians have amongst the worst outcomes in society.**

**Autistic people face discrimination, bullying and social ostracism all the time because we are different.**

- Autism Tasmania Community Members

Although Autistic Tasmanians aspire to a good life, as a group, they experience very poor life outcomes. On just about any measure, the Autistic community consistently have among the worst outcomes of any disability and vulnerable population groups including:

- Low rates of school completion, with high rates of school refusal.
- High rates of underemployment and unemployment.
- Extreme rates of mental ill-health (including a seven times greater risk of suicide).
- Poor health outcomes (20-36 years life expectancy gap).
- Extreme levels of marginalisation and social isolation.

**Failure to provide adequate and appropriate services for people with autism directly affects the degree to which they can participate in community and economic life**

- Office of the Public Guardian, Tasmania (Senate Autism Inquiry)

Autistic people facing extra challenges (such as having low income; limited English language skills; living with the consequences of systemic racism; or having substantial levels of impairment) may fare even worse.

These damaging outcomes are unacceptable and avoidable. They create significant harm and huge cost for Autistic people, their families and loved ones, and the broader Tasmanian community.

## Systems, policies, programs and community attitudes shape Autistic experiences.

*The systems, policies, programs and attitudes in Tasmania can make the difference between an Autistic person being able to contribute, or being left behind; being connected, or being isolated; being valued, or being marginalised; being enabled, or being disabled.*

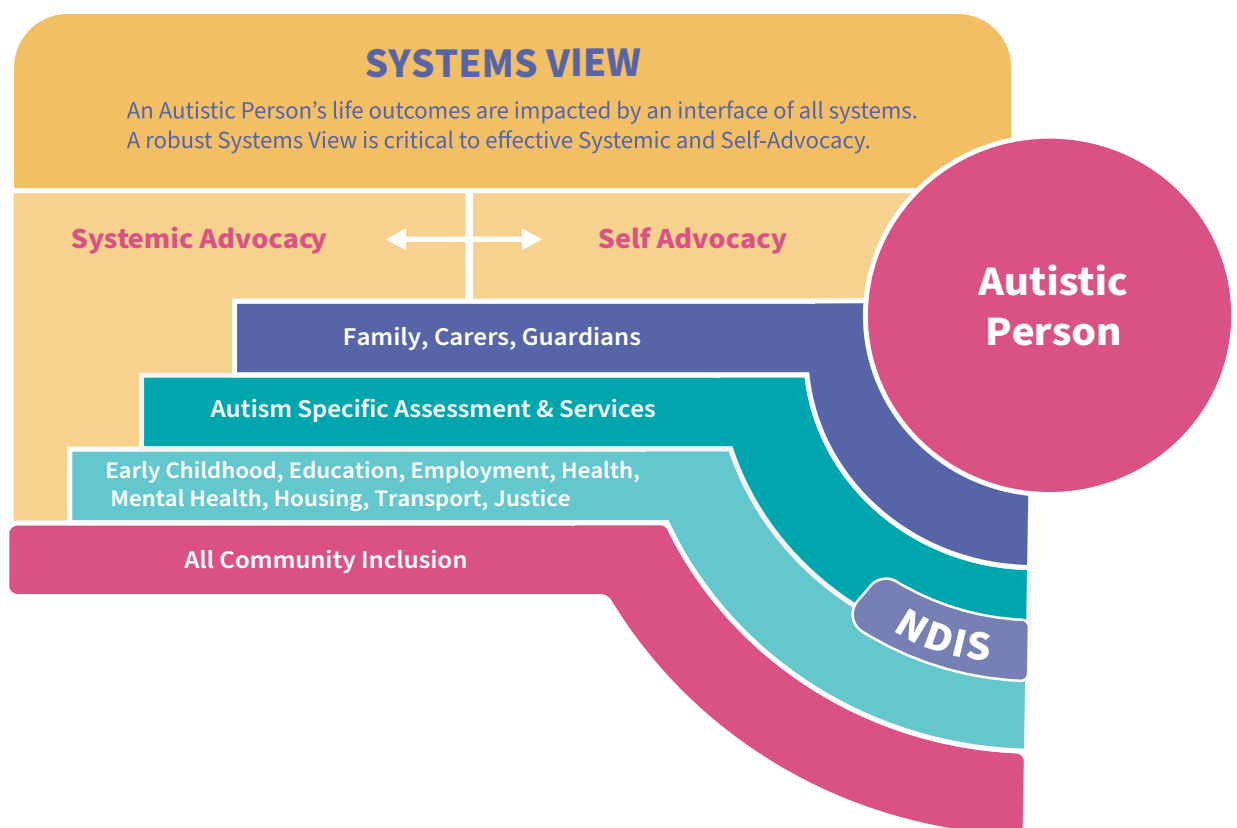
- CEO Autism Tasmania

A person's aspirations, opportunities and life outcomes are heavily impacted by their environment. Autism Tasmania uses a systems approach to understand the surrounding environment that influences an Autistic person's experience of life.

That is why we need to focus on systems change. This means shifting the conditions that create challenges and keep barriers in place for Autistic Tasmanians. In positive or negative ways, all of us can impact the factors that shape these conditions.

Immediate households, families and loved ones play a critical role in the life of an Autistic individual. Their capacity is directly influenced by the knowledge, connections and support they have.

Autistic people also interact with the broader community and with services and systems throughout their lives. These services are delivered by governments (national, state and local), as well as community organisations, local groups, sporting clubs, private service providers and businesses.



Community attitudes, laws and regulations, public policy settings, experiences of health care, family supports, education, employment, disability supports, aged care and social environments can be helpful or harmful; they can assist and empower or they can alienate and disempower.

Tasmania's Accessible Island (State Disability Plan) acknowledges that many challenges faced by people with disability are not due to the functional limitations of individuals but rather by the failure of society to meet their needs. This is widely referred to as the social model of disability (rather than a medicalised model that focusses on the individual's deficits).

Despite the high prevalence of autism, it remains a widely misunderstood condition, and the factors that serve to enable (or disable) Autistic people have been largely overlooked in many of the disability inclusion and accessibility efforts to date.

#### **The Senate Inquiry into Autism found that key drivers of poor outcomes include:**

- Low understanding of autism amongst community and key service provider workforces.
- Delays in diagnosis and early support.
- Complex and poorly integrated service environments.
- Services not designed to meet the needs of Autistic people.
- Autistic needs not being addressed in general disability strategies and approaches.

## **Specific approaches are needed to address the distinct needs of Autistic people.**

*Generic disability strategies have proven ineffective at improving life outcomes for Autistic people.*

- Senate Autism Inquiry (final report)

There are very few autism related initiatives in the state policy and program landscape. Tasmanians early momentum on developing autism responses, including through the previous Autism Advisory Panel, appear to have stalled.

While acknowledging the strong work undertaken in cross-disability policy, generic approaches rarely include sufficient focus on invisible disabilities, including autism.

Accessible Island (Tasmania's flagship disability strategy) and its requirements for accessible design (like the Accessible Event Guidelines) pay little attention to autism. There are a lack of voices for autism on key advisory groups and in state-funded advocacy services. Other major changes underway (youth justice, employment initiatives etc) appear to lack an autism lens.

**Recommendations by the Tasmanian Autism Advisory Panel (2018 final report) for a whole-of-government Tasmanian Autism Strategy have not progressed.**

## Tasmania is lagging compared to other states when it comes to Autism Policy.

*The systems, policies, programs and attitudes in Tasmania can make the difference between an Autistic person being able to contribute, or being left behind; being connected, or being isolated; being valued, or being marginalised; being enabled, or being disabled.*

- CEO Autism Tasmania

The high prevalence of autism, the poor outcomes relative to other disability groups, the distinct challenges faced, and the opportunity to make significant gains with a well targeted and tailored response, all create an imperative for autism-specific measures to be taken as a complement to broader disability approaches.

Except for the Tasmanian Autism Diagnosis Service, Tasmania lacks autism specific approaches adopted in other parts of Australia. Key examples include:

- A state autism plan in Victoria (which is a companion to the state's disability plan)
- Dedicated autism education initiatives. (Autism Education Hub in Qld and autism lead teachers in SA)
- Autism-specific health system reforms in WA
- An Assistant Minister for Autism, and a public sector Office for Autism in SA
- A state-funded public education / social behaviour change program campaign in Victoria
- Autism employment initiatives in Queensland and Victoria.

While Tasmania is very different to the mainland, it is important that we consider lessons from elsewhere, and how those ideas might be built upon in our context.

## Impending changes that will affect Autistic Tasmanians.

Right now, major changes to the policy, programs and systems environment that will impact the lives of Autistic people and their families are being developed in Tasmania, and at a national level.

There is a pressing need to join the dots between these upcoming changes, to ensure they are well informed, well designed, and seize the opportunity to deliver positive changes for Autistic Tasmanians. Equally critical is the need to ensure that the changes do not have unintended negative consequences for Autistic Tasmanians.

There are many factors that distinguish us from the mainland, which can be overlooked in national processes. It is therefore imperative that Tasmania brings coherent and robust positions to national discussions to ensure that resulting major changes will work well in our state's context.

**The very fluid reform environment comes with significant opportunities, as well as real risks for Autistic Tasmanians. We need to join the dots and ensure there are not unintended negative consequences.**

## Summary of Major Changes Underway: (see attachment 1 for more detail)

### **National Autism Strategy and National Roadmap on Health & Mental Health for Autistic People**

These landmark initiatives will create a dedicated and sustained national focus on Autistic community outcomes for the first-time ever. They have the potential to drive significant improvements, if well designed and implemented.

### **National Disability Insurance Scheme (NDIS) settings are changing following the major review that is now underway.**

Tasmania's Autistic community will be heavily impacted given the large representation of Autistic people (particularly children) on the Scheme. ***Likely directions of change*** include:

- Reducing the flow of children entering the NDIS (instead providing supports via other systems)
- Greater definition of what reasonable and necessary supports are and a menu of evidence-based supports that NDIS will fund (with preference for family-centred supports and those delivered in natural settings such as home or school).
- Different purchasing and pricing arrangements (including 'social markets' mechanisms such as preferred provider panels and changing incentives).
- Longer term plans and more contact with planners .
- Changed housing supports.

### **Supports Outside of the NDIS (Community Supports and Mainstream Services)**

It is widely agreed that supports outside of NDIS need to be significantly strengthened. This is the focus of negotiations between governments, implementation of Australia's Disability Strategy and the redesign of national funding programs (including the Information, Linkages and Capacity Building Program).

As the NDIS was rolled out, the Tasmanian Government (and other States) reduced their delivery and funding of other (non-NDIS) supports for people with disability. A recent Tasmanian Legislative Council Inquiry found that there are significant gaps and shortfalls for those not receiving NDIS supports and called for a range of actions. The Tasmanian Government has yet to publish a response to the Inquiry's recommendations.

### **A national Early Years Strategy (for 0–5-year-olds and their families)**

Currently being developed, this Strategy is expected to have a strong focus on children with disability and supports outside of the NDIS. When considered together with implementation of the 'It takes a Tasmanian Village' framework and the roll out of universal pre-school, this provides significant opportunity to strengthen supports for young children and their families.



## **Tasmania's next disability strategy**

This is a highly important piece for the Autistic community as it will guide disability related priorities, actions and investments in Tasmania for the next decade. The current Tasmanian disability strategy (Accessible Island) pays little attention to autism, despite its high prevalence.

## **The Disability Royal Commission**

Reporting later in 2023, the Commission is expected to make some grave findings and pointed recommendations that will drive major changes to prevent and address discrimination, abuse, neglect and exploitation experienced by the disability and Autistic community.

## **Disability Inclusion Act (Tasmania)**

Tasmania is developing progressive new disability law to advance the rights and inclusion of people with disability, with Tasmania's first ever Disability Inclusion Commissioner being appointed.

## **Jobs Tasmania's focus on transitions and employment for young people**

(as part of the broader youth wellbeing strategy) is a significant development. To successfully deliver on its mandate around diversity and inclusion, it is critical that autism-responsive approaches are embedded in this initiative.

## **Autistic Tasmanians need to “inform the reforms”**

*With a National Autism Strategy being developed, together with major changes that will impact Autistic Tasmanians, there has never been a more important time for cooperative action.*

Meaningful engagement and active involvement of Autistic Tasmanians, their families, loved ones and allies is critical to shaping future reforms and informing how change is implemented. Autism Tasmania has combined experiences shared by our community, with available data and policy analysis to develop this Autism in Tasmania: State of the State Discussion Paper.

This paper seeks to strengthen our collective understanding of the circumstances faced by Autistic Tasmanians. It also provides some thought starters about practical opportunities for improvements in the current environment. The paper is intended to help inform and advance discussions with Autistic people, their families and loved ones, government agencies, community organisations and service providers.

We thank the community members and organisations who generously provided input into draft versions of this paper. Their insights and lived experiences are quoted throughout this paper.

To influence change, we need to work together.

# 20 Thought Starters: Ideas for Action

	Ideas for action	Why it is needed	Voices
A dedicated and co-ordinated approach to improve outcomes for Autistic Tasmanians.	<p><b>1. Develop a dedicated Tasmanian Autism Plan, co-designed with Autistic people, families and their representatives.</b></p> <p><b>This could be a companion piece to Tasmania's next State Disability Plan.</b></p>	<ul style="list-style-type: none"> <li>Tasmania has a large Autistic population, with many experiencing very poor life outcomes.</li> <li>Autism considerations are largely missing from Tasmania's current policy and program environment.</li> <li>A systemic approach in Tasmania will allow us to take up the opportunities and reduce the risks associated with major national changes underway that will impact Autistic Tasmanians (such as the NDIS reboot).</li> </ul>	<p><i>Generic disability strategies have proven ineffective at improving life outcomes for Autistic people.</i></p> <p><b>- Senate Autism Inquiry</b></p> <p><i>The systems, policies, programs and attitudes in Tasmania can make the difference between an Autistic person being able to contribute, or being left behind ... being enabled, or being disabled.</i></p> <p><b>- CEO Autism Tasmania</b></p>
Timely and reliable autism assessments.	<p><b>2. Reduce public waiting lists to no more than three months for children needing autism assessment and diagnosis.</b></p> <p><b>3. Ensure robust and consistent approaches to assessing autism across Tasmania, based on the National Guideline.</b></p>	<ul style="list-style-type: none"> <li>Current 18 month waits delay access to the early supports that can make a huge difference to a child's development.</li> <li>Quality and reliable autism assessments help Autistic people and their families to better understand themselves and connect with community and supports.</li> </ul>	<p><i>Given the cost and wait times, getting an autism assessment is a privilege for a lot of people.</i></p> <p><i>Autistic identification helps us to come together as part of a community.</i></p> <p><b>- Tas Autism Community</b></p>
Disability supports that are easier to access.	<p><b>4. Explore innovative ways to purchase, provide and arrange disability services to improve efficiency and outcomes for Tasmanians. Expand supports in pre-school and schools.</b></p>	<ul style="list-style-type: none"> <li>The NDIS will bring major changes for Autistic Tasmanians.</li> <li>Tasmania has significant workforce shortages; we need to deliver supports in a way that makes best use of limited resources.</li> </ul>	<p><i>There are limited options for therapy services for children leading to unacceptable wait times.</i></p> <p><b>- Tas Legislative Council Disability Services Inquiry 2022</b></p>

Stronger support for families and carers at risk

**5. Strengthen assistance for households needing supports to cope, stay safe, stay together or reunite.**

- Autistic children and young people are over-represented in Out of Home care. This increases risk of criminalisation and homelessness.
- Timely supports to build household resilience and capacity make a big difference.

Autistic students are setup for success

**6. Establish a dedicated focus on improving outcomes and experiences for Autistic students (across the education continuum) backed by targeted approaches.**

**7. Support the education workforce to build autism understanding and include autism training as part of educator registration requirements.**

**8. Establish a service/ pathway to support the re-engagement of Autistic children and young people into education.**

- Autistic students have high rate of school refusal and early school leaving. Much can be done to change this.
- Tasmania will soon offer two years of pre-school; this represents a major opportunity to strengthen inclusion of Autistic children in education.

*We received far fewer calls about school problems when Tasmania's education department had autism advisers.*

*Where schools are interested, adaptive, flexible ... it works. One of my boys was really thriving at school because his teacher set up a good, well-structured environment. The next year ... was a disaster.*

**- Tas Autism Community**

Autistic skills and talent in the Tasmanian workforce

**9. Embed autism-responsive approaches into Job's Tasmania initiatives.**

**10. Pilot autism-focussed employment programs in a range of sectors and settings, including Tasmanian State Services.**

- Autistic Tasmanians overwhelmingly want to work, but face very high rates of joblessness and underemployment.
- Major Tasmanian employment reforms underway (including youth-focussed employment projects and Regional Jobs Hubs) could be designed for autism-inclusion.

*Entering adulthood with no job, no vocation, is a real setback.*

*I had years of unstable employment, in and out of work.*

**- Tas Autism Community**

## Better health and mental health.

**11. Develop a Tasmanian Roadmap for Health & Mental Health for Autistic people to complement the National Health and Mental Health Roadmap for Autistic people that is being developed.**

- The Autistic community has major health (20-36 life expectancy gap) and mental health challenges (including a 7x increased risk of suicide).
- Autism responsiveness across the health and mental health system is urgently needed.
- Tasmania's upcoming disability health strategy represents an opportunity for a dedicated focus on autism.

*As my dad aged, he was very resistant to accepting care from others, taking medications or changing his routines*

*My child's diet is very limited. He will only eat white foods.*

**- Tas Autism Community**

## Being a part of community life.

**12. Create more autism accessible events, venues and environments, refresh the Tasmanian Governments Accessible Event Guidelines to address autism accessibility considerations and Position the Tasmanian Government as an exemplar in autism-friendly environments incentivising others to follow.**

- Many Autistic people and their families/carers are highly isolated.
- Autism, and ways to support and include Autistic people is not well understood by the broader community.
- There is little focus on autism accessibility measures (such as sensory mapping, social scripts and quiet spaces).
- Connections between Autistic Tasmanians (and families/carers) supports wellbeing and builds confidence.

*Autistic people face discrimination, bullying and social ostracism all the time because we are different*

*I am less isolated and have more things to do around Hobart thanks to the people I have met through Peer Support: the Autistic Way.*

**- Tas Autism Community**

**13. Partner with community organisations to extend the reach and impact of Autistic peer support, including for groups at higher risk of marginalisation.**

## Rights and voice.

**14. Ensure Autistic people and their organisations are included on key state and local government disability/inclusion advisory committees, and national autism reform processes.**

- The Disability Royal Commission is highlighting that Autistic people are particularly vulnerable to abuse, neglect and discrimination.
- Autism perspectives are under-represented on governmental and community-based inclusion and disability advisory groups.
- The Tasmanian Government has no autism-specific advisory groups and does not fund autism advocacy.
- Tasmania's Flourish (mental health consumers) model provides a good model for enabling and building capability for lived experience participation.

*Young people ... unable to live in the family home because of complex disability support needs can face significant challenges finding safe, stable housing appropriate to their needs.*

**- Under 16 Homelessness Tasmanian Policy Framework**

**15. Support dedicated autism advocacy – systemic, individual and self-advocacy to amplify the experiences and advance the rights of Autistic Tasmanians.**

## Housing solutions.

**16. Markedly expand the availability of 'robust' housing, including public and social housing stock and respite accommodation.**

**17. Ensure efforts to address homelessness (including youth homelessness initiatives) are designed and implemented to address the circumstances of Autistic people experiencing, or at risk of, homelessness.**

- Autistic people face increased risk of homelessness given their over representation in out of home care and the justice system.
- There is a lack of 'robust' housing in public/social housing stock, emergency respite and SDA stock. The 'robust' category is designed to reduce the risk of injury for people with complex behaviours and those that live with or visit them.

*Without state investment in dedicated autism advocacy and representation, Tasmania's Autistic community are at risk of being disadvantaged in the major reform processes underway.*

**- Australian Autism Alliance**

## Better experiences with the justice system.

**18. Develop guidance, tools and training to equip the justice system and workforce to better support the specific needs of Autistic victims, witnesses, accused/perpetrators.**

**19. Ensure the increased risk factors experienced by Autistic people are specifically addressed in future responses to sexual abuse.**

**20. Support cognitive assessment and NDIS eligibility screening for people interacting with the justice system who display developmental or complex behavioural concerns.**

- Autistic people interact with the justice system at comparatively high rates as both victims and those accused of crime. They are more likely to have negative and potentially traumatising encounters with the criminal justice system.
- Much work has been done internationally that could inform autism-responsive approaches in Tasmania's justice system.

*While behavioural or developmental concerns may be well recognised in a young person and appropriate paediatric referrals made – they still may not be assessed for up to 24 months.*

*Left waiting and unsupported, these children and young people are more likely to come to harm, and exhibit their distress through escalating antisocial behaviour, with long term and sometimes lifelong consequences.*

**- Tasmanian Draft Youth Justice Blueprint 2022**

## What Helps or Hinders: The factors influencing the life experiences of Autistic people.

The overarching factors that influence the life experiences of autistic people include community acceptance, autism friendly environments, access to assessment and diagnosis for (all ages), neuro-affirming support and services, Autistic representation, and stable housing.



### Pregnancy and Birth

Autistic mums need extra help. They are more likely to suffer pre-natal and post-natal depression and breastfeed at lower rates

#### What Helps

- *Autism informed and sensory-sensitive health and maternal health supports.*
- *Social stories about pregnancy and birthing.*
- *Peer connections.*

#### What Hinders

- *Traumatic birthing experiences*



### 0 - 3 Years of Age

Early identification and early family supports can make a big difference.

#### What Helps

- *Early identification of Autistic signs and access to timely and affordable assessment and diagnosis.*
- *Family centred supports and capacity building.*
- *Enhanced child health and parenting supports.*
- *Connections with other families.*
- *Inclusion in playgroup, childcare and activities (swimming, music classes etc).*

#### What Hinders

- *Delayed identification*
- *Long waits for assessment and diagnosis.*



### 3 - 8 Years of Age

Ability to self-regulate and good supports and connections for the family is a major issue for both child and family well-being. Two-years of inclusive pre-school could help us get off to a better start in education.

#### *What Helps*

- *Being welcomed and included at pre-school and school*
- *Being welcomed into extracurricular activities such as sport, drama etc.*
- *Connections with other families.*
- *Family capacity building and supports (including access to respite care if needed).*
- *High quality early childhood supports in natural settings (home, pre-school and school).*
- *Timely and affordable assessment and diagnosis.*

#### *What Hinders*

- *Not attending pre-school.*
- *Lack of support for family (increased risk of child relinquishment).*
- *Missing out on normal life experiences because of spending too much time in therapy.*



### 8 - 12 Years of Age

Puberty is a big transition for everyone, but especially Autistic young people. Autism in girls is often detected late than in boys.

#### *What Helps*

- *Inclusion at school.*
- *Friendships.*
- *Family capacity building, including navigating transition to puberty.*
- *Family supports (including access to respite care if needed).*
- *High quality disability supports (where needed).*
- *Timely and affordable assessment and diagnosis.*

#### *What Hinders*

- *Bullying and marginalisation.*
- *Lack of appropriate adjustments to support school engagement.*
- *School refusal/ disengagement.*
- *Lack of support for family (increased risk of child relinquishment).*





## 13 - 17 Years of Age

Sexuality and orientation are big issues with a high proportion of Autistic people identifying as LGBTQIA+. Early school leaving is common Autistic children and teenagers are 10 times more likely to have a hospital admission.

### *What Helps*

- *Inclusion at school.*
- *Positive friendships and relationships.*
- *Autistic connections.*
- *Careers guidance, work experience, student jobs.*
- *Autism-responsive mental health and health care.*
- *Tailored reproductive health information.*
- *Family supports (including access to respite care if needed).*
- *Disability supports (where needed)*
- 

### *What Hinders*

- *Bullying and marginalisation.*
- *Lack of appropriate adjustments to support school engagement.*
- *Early school leaving.*
- *Lack of support for family (teen years can involve escalated conflict and risky behaviours)*
- *Misdiagnosis of mental health issues.*



## 17- 25 Years of Age

Being equipped to launch into adulthood is so important. Entering adulthood with no job, no vocation, is a real setback.

### *What Helps*

- *Positive friendships and relationships.*
- *Autistic connections.*
- *Inclusion in post-secondary education.*
- *Employment that matches skills and interests.*
- *Autism-responsive mental health and health care.*
- *Disability supports (where needed).*

### *What Hinders*

- *Lack of independence (and over dependence on others).*
- *Not working, training of studying.*
- *Autistic burnout.*
- *Isolation and marginalisation.*





## 25 - 45 Years of Age

So many adults discover they are Autistic after their child receives a diagnosis.

### *What Helps*

- *Positive friendships and relationships.*
- *Autistic connections*
- *Autism-responsive mental health and health care.*
- *Tailored support for birth and parenting.*
- *Disability supports (where needed).*

### *What Hinders*

- *Unemployment or unstable employment.*
- *Autistic burnout.*
- *Lack of independence (and over dependence on others).*
- *Isolation and marginalisation.*



## 45 - 65 Years of Age

I had years of unstable employment, in and out of work. Many Autistic people have a lot of health issues, which can really escalate in middle age.

### *What Helps*

- *Positive friendships and relationships.*
- *Autistic connections.*
- *Autism-responsive mental health and health care.*
- *Disability supports (where needed)*

### *What Hinders*

- *Unemployment or unstable employment.*
- *Autistic burnout.*
- *Lack of independence (and over dependence on others).*
- *Isolation and marginalisation.*



## 65 + Years of Age

As my dad aged, he was very resistant to accepting care from others, taking medications or changing his routines. Autistic people have higher rates of dementia.

### *What Helps*

- *Autism responsive aged care, including assessments that factor in autistic conditions, sensory care and interception.*
- *Positive friendships and relationships.*
- *Autistic connections*

### *What Hinders*

- *Unemployment or unstable employment.*
- *Autistic burnout.*
- *Lack of independence (and over dependence on others).*
- *Isolation and marginalisation.*

# Much can Help Improve Outcomes for Autistic Tasmanians

From conception to old age, and right through an Autistic person's life journey, there are many factors, and multiple systems, influencing their aspirations, opportunities, experiences and outcomes.

The next part of this paper zooms in on key areas likely to attract significant focus in the next version of Tasmania's State Disability Strategy (Accessible Island #2) and the National Autism Strategy.

*The following part of this paper focuses on ten of the key areas and systems impacting the lives of Autistic Tasmanians.*

1. *Autism assessment & diagnosis*
2. *Autism services and supports*
3. *Family and carer support*
4. *Education*
5. *Employment*
6. *Health & Mental Health*
7. *Social and community inclusion*
8. *Rights and advocacy*
9. *Justice system*
10. *Housing*

*For each of the ten areas, this paper seeks to start building a picture of the current state of play in Tasmania by identifying:*

- *Key issues facing Autistic Tasmanians and their families.*
- *Promising approaches in Tasmania and elsewhere that could be enhanced, built on or replicated for the benefit Autistic Tasmanians.*
- *Opportunities for action.*
- *Key decision makers and relevant reform processes.*

We know our picture will not be complete. There is significant knowledge, experience, ideas and data held by others (individuals, government agencies, community organisations, service providers) that can fill the gaps and contribute to more comprehensive representation of the circumstances facing Tasmania's Autistic community and the opportunities for the broader community.

There are considerable shortcomings in data relating to Autistic Tasmanians. Availability of the National Disability Data Asset (anticipated for release in 2024) together with the next version of ABS's Autism in Australian report (due mid 2024) should help to partially bridge this gap and provide important baselines against which to track and measure progress.

# A State Autism Plan

The high prevalence of autism, the poor outcomes relative to other disability groups, the distinct challenges faced, and the opportunity to make significant gains with a well targeted and tailored response; all create an imperative for autism-specific measures to be developed as a complement to broader disability approaches.

Recommendations by the Tasmanian Autism Advisory Panel (2018 final report) for a whole-of-government Tasmanian Autism Plan have yet to be progressed.

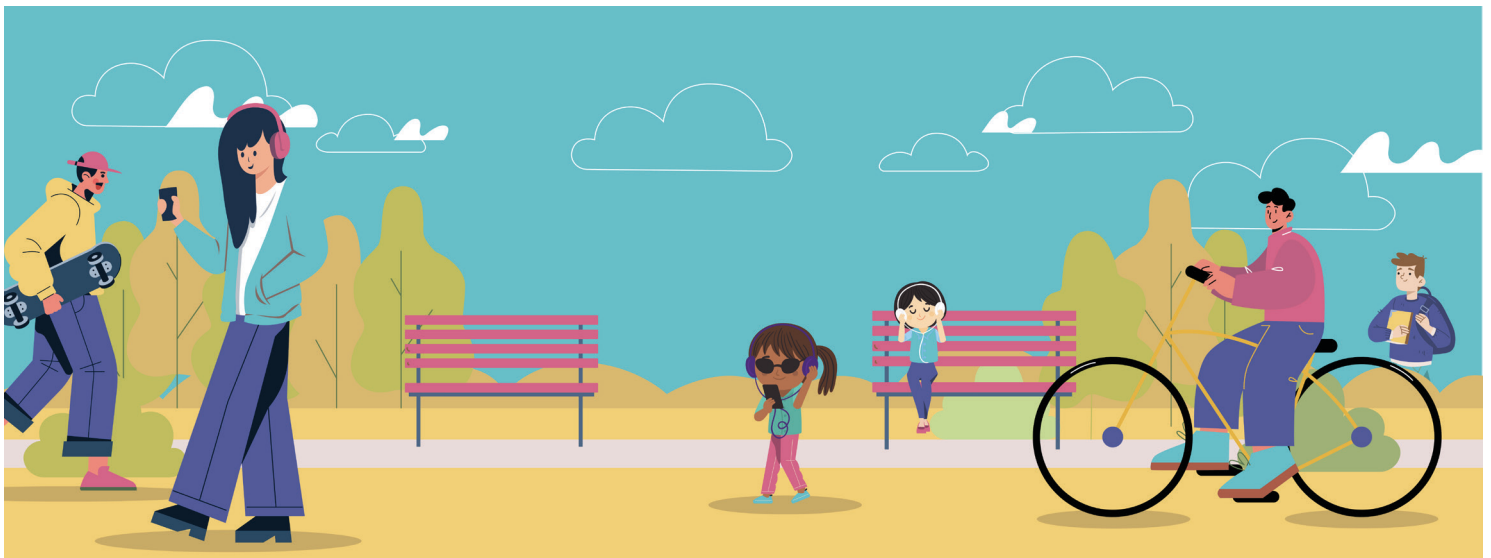
To avoid a piece meal, haphazard approach, Tasmania needs an overarching autism plan that:

- Ensures mutually reinforcing approaches across and between different parts and levels of government
- Harnesses community and business support
- Measures and tracks progress.

A state autism plan could standalone or form a dedicated component of the next version of Tasmania's state disability plan.

## Ideas For Action

1. Develop a dedicated Tasmanian Autism Plan, co-designed with Autistic people and their representatives.

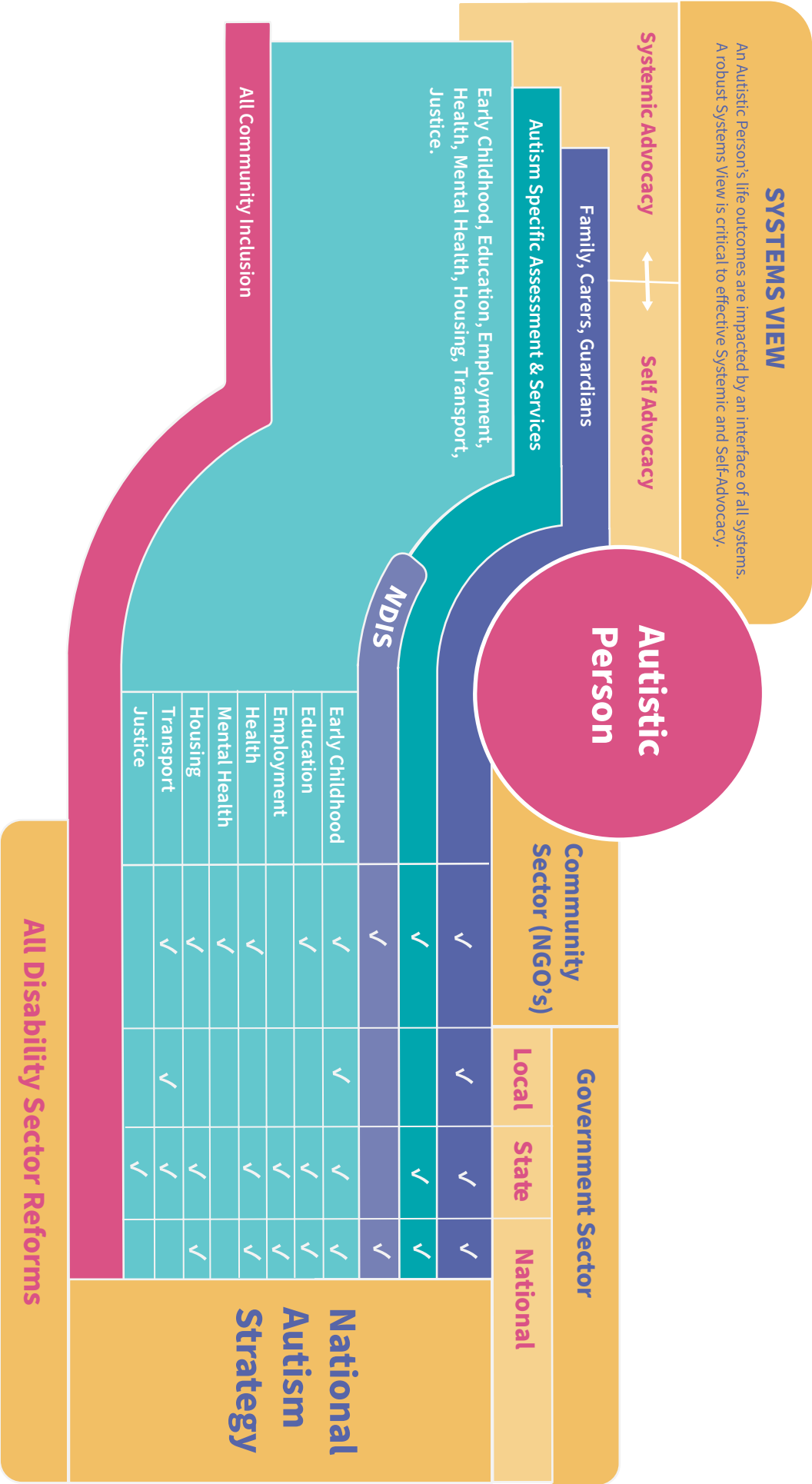


***“General disability strategies have failed to improve outcomes for Autistic Australians - A whole decade on from the inception of the NDIS”***

***- Select Committee on Autism Commonwealth of Australia  
March 2022***

***“Mainstream services and even general disability services are not designed for Autistic people.”***

# A Systems View Will Make A Difference



# Autism Assessment/Diagnosis

Every moment counts in the development of infants, children and young people with autism. Early diagnosis enables access to the time-critical services and supports which can deliver developmental benefits and lead to better life outcomes. Most children seeking autism assessment and diagnosis in Tasmania are seen, for no charge, by the Tasmanian Autism Diagnostic Service (up to 18 years) or St Giles (infants and younger children).

Children in Tasmania most typically receive an autism diagnosis at the ages of two or three years old.<sup>3</sup> Autism in females is often not detected until school years.

Many adults are also seeking autism diagnosis (particularly if their children receive a diagnosis) The reported benefits of diagnosis include improved self-understanding and acceptance, a sense of belonging and identity, access to strategies and supports to improve their situation, and diagnosis being a helpful explainer for others.<sup>4</sup>

*Given the cost and wait times, getting an autism assessment is a privilege for a lot of people. We took our child to appointments in Melbourne to avoid the long wait times.*

- Autism Tasmania Community Members

## Key Issues

- Long wait lists for children needing an autism assessment and diagnosis. Public wait lists exceeded 18 months in 2021-22.<sup>5</sup> Autism Tasmania estimates over 300 children are currently awaiting public diagnostic services.
- High out-of-pocket costs for private assessments (around \$2000 for children and more for adults). Workforce challenges (including limited availability of paediatric psychiatrists and allied health professionals with the skills and experience to undertake assessments).
- Misdiagnosis, particularly when there are intersecting mental health conditions.
- Autism frequently goes undiagnosed or misdiagnosed in First Nations communities.<sup>6</sup>
- Inconsistency in quality of assessment, including for those using on-line services.

## Promising approaches

- The Tasmanian Autism Diagnostic Service (TADS) was commended by the Senate Autism Inquiry as a good example of an effective interface between government agencies (education and health).
- Training Child Health Nurses and other allied health professionals in the early identification of autism (as part of the Social Attention and Communication Surveillance research project) provides an important screening opportunity.

## Better Medicare rebates

*From 1 March 2023, the age cap on Medicare rebates for autism assessment and diagnosis was lifted from 13 to 25 years and additional rebateable items added.*

## National Autism Assessment Guideline

The Guideline is being reviewed and updated. Work is also underway to support operationalisation the Guideline to improve consistency in diagnostic practices.

## Ideas For Action

2. Reduce public waiting lists to no more than three months for children needing autism assessment and diagnosis.
3. Ensure robust and consistent approaches to assessing autism across Tasmania, based on the National Guideline, using TADS as an exemplar.

## Key decision makers and Processes

**Led by the Federal Minister for Disability**

*Development of National Autism Strategy*

**Health and Mental Health Ministers**

*National Roadmap Health & Mental Health for Autistic People*

**Tasmanian Minister for Disability**

*Development of Tasmania's next state disability strategy (Accessible Island #2) and Tasmanian contribution to the National Autism Strategy.*

**Autism assessment providers**

*Implementation of National Autism Assessment Guideline*

# Autism Supports and Services

The need for autism related supports varies widely amongst Tasmania's Autistic community. Some will thrive with an inclusive environment, responsive mainstream services and an understanding of their autism. Others may need dedicated supports whether intermittent or ongoing, low level or highly intensive.

*There are limited options for therapy services for children leading to unacceptable wait times.*

- Legislative Council Report, Disability Services in Tasmania 2022

## NDIS numbers:

- 4,200 Autistic Tasmanians are on the NDIS.
- Autism is the most prevalent primary disability among Tasmanians receiving NDIS supports (35%).
- Most children and young people (under 25 years) receiving NDIS supports are Autistic.

## Key Issues

- There is little support, outside of the NDIS, for Autistic Tasmanians.<sup>7</sup>
- Workforce:
  - Shortages and high workforce turnover
  - Little choice between service providers
  - Long wait lists
  - Allied health professionals leaving the public system to join private NDIS services
  - Low understanding of autism among key workforces, including NDIS planners and care workers.
- Service gaps for people with complex needs or challenging behaviours reflects provider reluctance to take them on.
- Children are often taken out of school to go to therapy and parents spend a lot of time taking them to multiple appointments.
- Lack of culturally responsive services for First Nations, with significant additional barriers to accessing supports.<sup>8</sup>
- NDIS and service systems are hard to navigate:
  - Hard to know which services and supports are good quality and neuro-affirming.
  - People get caught (and at risk of being over-served) by the one provider.
  - Limited funding for support co-ordination to assist people to make best use of their plans.
  - Particularly acute problems for people with low English proficiency.

*It is not uncommon for services (particularly those operating in a commercial environment) to withdraw supports which can result in people with no specific health need being admitted to hospital to ensure their safety.*

- Tasmania's Office of the Public Guardian (Senate Autism Inquiry)



*Some providers target people with big NDIS plans and encapsulate them. Support Co-ordination becomes the gateway and they get funnelled internally into the providers services. It's a new form of institutionalisation. They take everything.*

- Autism Tasmania Community Member

Promising approaches

- The major NDIS ‘reboot’ will potentially dramatically affect the Autistic community, given their high numbers on the Scheme. The upcoming changes create both a huge opportunity for improvement and substantial risks.
- The Allied Health Expansion Project (a Tasmanian Government/ Uni Tas partnership) introduced Physiotherapy, Occupational Therapy, Speech Pathology and Dietetics courses from 2022. It aims to build capacity for these professionals to work with people with autism.

Ideas For Action

- 4. Explore innovative ways to purchase, provide and arrange disability services to improve efficiency and outcomes for Tasmanians. Expand supports (including NDIS services) in pre-school and schools.

Key decision makers and Processes

**Led by the Federal Minister for Disability**

*Development of National Autism Strategy*

**Minister for the NDIS**

*NDIS Review and NDIS ‘reboot’*

**Tasmanian Minister for Disability**

*Renegotiation of NDIS, development of Tasmania’s next state disability strategy (Accessible Island #2), Tasmanian contribution to the National Autism Strategy.*

**Tasmanian Minister for Education, Children and Youth**

*Supports in pre-school and school.*

# Support for Families and Carers

Every Autistic child has someone caring for them, and many Autistic adults require care, either occasional or ongoing.

Because autism often runs in families, many carers of Autistic children are also on the spectrum.

Equipping families and carers, from the earliest days, with autism-support capabilities and knowledge, carer support services and connections to peers and opportunities for respite, can make a huge difference to the home environment, family dynamics and outcomes for everyone involved.

More than one-third (37%) of children in out of home care have a disability. Many are Autistic and display behaviours of concern.

*Despite the wellbeing of parents and carers being critical to the success of Autistic people, there is overwhelming evidence that support for parents and carers is currently inadequate.*

- Senate Autism Inquiry Report 2022

## Key Issues

- Families and carers often experience social isolation, burn out, health and wellbeing challenges, and family breakdown.
- Lack of specialist emergency respite care and intensive supports for families where there are challenging behaviours.
- Some Autistic children attend school for restricted hours and are excluded from excursions, camps, after school and care and holiday programs. They spend more time at home than their peers, creating a greater load on parents and carers.
- Autistic children are relinquished or placed into out of home care at disproportionately high rates.
- The Children and Young Persons' Program (part of Tasmania's Family Violence Counselling and Support Services) highlighted the need for a clear framework and specific resources to assist children with autism to engage fully in the therapeutic process for recovering from family violence trauma.
- The national Early Days program (aimed at parents/carers of Autistic children) has ceased. While there are generic disability workshops available<sup>9</sup>, these do not cover in detail the distinct challenges and enablers for supporting the development of an Autistic child.
- Many Autistic young people are entering adulthood without the necessary skills for independence (decision making, finance literacy, working, living).
- Ageing parents/carers are concerned about who will provide future care for their Autistic loved ones.

## Promising approaches

- Investments under the Tasmanian Government's "It Takes a Tasmanian Village"<sup>10</sup> in preventative supports for Tasmanian families experiencing complexity (such as Bringing Baby Home, the Sustained Home Nursing Visit Program and Child and Family Learning Centres outreach and the Strong Families, Safe Kids Action Plan) are designed to avert problems before they occur or address them in the early stages. It is critical these programs are autism responsive and know how to connect with NDIS and disability supports.
- Care2Serve (delivering the Carer Gateway) partners with Autism Tasmania to reach carers of Autistic people and provides carer coaching and advice, facilitated groups and emergency respite.
- Peer networking and support groups play a critical role in strengthening knowledge and connection. Autism Tasmania and the Association for Children with Disabilities provide peer support for families and carers.

**Victoria's Family Services Specialist Disability Practitioners** work with family services providers and families to navigate access to supports (particularly for families with Autistic children with behaviours of concern).

*Providing access to regular respite care and core NDIS supports (such as a support worker visiting a couple of times a day) is helping families to cope, be safe and stay together.*

## Ideas For Action

5. Strengthen assistance for families needing increased supports to cope, stay safe, stay together or reunite (including through ensuring they are accessing appropriate NDIS/disability supports).

## Key decision makers and Processes

**Led by the Federal Minister for Disability**

*Development of National Autism Strategy*

**Health and Mental Health Ministers**

*National Roadmap Health & Mental Health for Autistic People*

**Tasmanian Minister for Disability**

*Development of Tasmania's next state disability strategy (Accessible Island #2) and Tasmanian contribution to the National Autism Strategy.*

**Tasmanian Minister for Education, Children and Youth**

*Out of home care.*

# Education

Education is key to life chances. Despite their high numbers as a group, Autistic students have appalling outcomes at school, and in Further and Higher education – worse than most other disability and vulnerable population groups. Autistic students are in every Tasmanian school, TAFE and university. Nearly every classroom will have at least one Autistic student.

Most Autistic students are attending mainstream education institutions, while a small proportion meet the criteria to attend Tasmania's few disability specialist schools.<sup>11</sup> Schools and universities have a needs-based funding model for students meeting eligibility requirements for disability funding (including some Autistic students).<sup>12</sup> TAFE does not.

Access to inclusive early learning, schooling, training and university enables Autistic people to harness their talents and actively participate in community and economic life.

There is huge potential to lift the educational attainment of Autistic people through much higher rates of school, TAFE/VET and university completions.

Attendance at community preschool improves the likelihood of obtaining National Minimum Standard for Grade 3 NAPLAN, compared to other service types. Autistic students are half as likely to complete Year 10 than the general population.

TAFE is the most common post-school destination for Autistic young people. Autistic students are half as likely to complete VET or University courses than those with other disabilities.

## Key Issues

- Variable autism understanding and inclusion practices amongst educators and education settings.
- Reasonable adjustments are not well understood and are not consistently applied, ignoring student rights under the Disability Standards for Education.
- Restricted attendance is over-used. Children with challenging behaviour are often excluded and some are not permitted or supported to attend full time.
- Widespread experiences of bullying and exclusion.
- High rates of unplanned school moves and high numbers moving to home schooling.
- Autistic students are over represented among those experiencing school refusal, school disengagement, and early school leaver numbers.
- Many Autistic school leavers do not successfully moving into further study or employment.
- In higher education, significant numbers of students do not disclose their autism for fear of discrimination. Even where disclosure is made, appropriate adjustments are often not understood or implemented.

*One of my boys was really thriving at school because his teacher set up a good, well-structured environment. The next year, with a new teacher and open plan learning, was a disaster. Some kids seem to be on conveyor belt... from early school dropout ... entry level TAFE ... day programs.*  
- Autism Tasmania Community Members

*We received far fewer calls about school problems when Tasmania's education department had autism advisers.*

*Where schools are interested, adaptive, flexible ... it works.*

*A common practice amongst the worst of our schools is exclusion. Many schools do not seem to be adjusting in the way the Disability Standards for Education require.*

- Autism Tasmania staff members

## Promising approaches

- Universal access to early learning in the year before kindergarten is being introduced. This will build on the [\*Working Together Initiative\*](#) (which offers free early learning to select three-year-olds, including those with marked developmental delay). Evaluation of this program is consistent with the broader evidence base, showing that two years of quality early learning before school strengthens developmental outcomes, particularly for students with disability. Provided these early learning settings are inclusive and autism-responsive, this initiative could generate substantial benefits for Autistic children.
- [\*TasTAFE Disability Action Plan\*](#) contains important actions including: meeting DSE obligations; ensuring non-discriminatory and accessible selection and enrolment procedures; encouraging disability disclosure throughout the student lifecycle; specialist staff to coordinate support; a comprehensive range of supports; and reasonable adjustments and support for transitions.
- Skills Tasmania's Disability Action Plan commits to fostering flexible, high quality and innovative VET opportunities for people with disability; ensuring access to wrap-around support services, reducing barriers to access and participation in post-compulsory education; and developing evidence-based VET pathways for people with disability.
- The University of Tasmania provides peer mentoring for Autistic students and hosts the Australian Disability Clearinghouse on Education and Training (an online resource on inclusive practices in post-secondary education).
- Significant autism related resources and training is available to support schools and teachers (such as Positive Partnerships Program<sup>13</sup>, NCCD resources<sup>14</sup>, Autism CRC and autism education hubs operating in other states).

### Strong focus on Autism education in other states

#### South Australia (from 2023)

- Autism Inclusion Teacher in every primary school and more specialist staff
- Increasing the number of staff in preschools with qualifications in autism
- Expanding early childhood support services in children's centres
- Supporting schools to sign up to the Autism Friendly Charter

## Ideas For Action

6. Establish a dedicated focus on improving outcomes and experiences for Autistic students (across the education continuum) backed by targeted approaches.
7. Support the workforce to build autism understanding, including through autism training as part of educator registration requirements.
8. Establish a service/pathway to support re-engagement of Autistic children and young people into education.

## Key decision makers and Processes

### Led by the Federal Minister for Disability

*Development of National Autism Strategy.*

### Health and Mental Health Ministers

*National Roadmap Health & Mental Health for Autistic People.*

### Tasmanian Minister for Disability

*Development of Tasmania's next state disability strategy (Accessible Island #2) and Tasmanian contribution to the National Autism Strategy.*

### Tasmanian Minister for Education, Children and Youth

*Education reform policy.*

# Employment

Autistic Tasmanians overwhelmingly want to work, yet employment rates across the community are very low, with extreme rates of unemployment and underemployment. In a tightening labour market, they represent a huge pool of untapped talent.

Research shows there is a sound business case for the employment of neuro-divergent people as they make reliable and skilled employees who can bring their workplaces innovative perspectives, high productivity and reputational enhancement.

Many employers, if equipped with the know-how and supports, are eager to take on Autistic staff.

**According to the 2018 ABS Autism in Australia Report, Autistic people are 3 times more likely to be unemployed than others with disability, and are unemployed at nearly 8 times the rate of people without disability**

*So many of the men in my Autistic adult peer group have either never had a job or have not been able to sustain their work.*

*Autistic characteristics can be misinterpreted as being difficult, which can lead to HR issues...*

*Challenges with making small talk and socialising in neurotypical ways stop career progression.*

- Autism Tasmania community members

## Key Issues

- Lack of effective support for transitioning between education and employment.
- Low rates of employer understanding about how to support and enable Autistic staff through accessible recruitment and work-based processes.
- Lack of autism responsive support across employment services (Jobs Tasmania, Disability Employment Services, Workforce Australia etc).
- Over-representation of Autistic people in closed/segregated employment (Australian Disability Enterprises).
- Risk of losing Disability Support Pension and concessions by taking employment (which may be difficult to resume if the job doesn't work out).
- Autistic burnout.

## Promising approaches

- Jobs Tasmania (with the Youth Network of Tasmania) is establishing a Youth Employment Community of Policy and Practice. Diversity and inclusion practices are said to be embedded in all aspects of the approach. The Youth Connectors program will link young people with industries, jobs, further education and training opportunities in their local area, supported by the new Regional Jobs Hubs network. A Youth Transitions Plan (for 18-25-years-olds) is being developed.
- Employ Me pilot youth project is an ILC funded initiative led by the Brain Industry Assoc Tas in collaboration with ACD Tas. If well designed, there is potential for Autistic involvement.

People with autism often have to “make do” with services designed for people with intellectual disabilities, which are often not well aligned...supported employment options can be in busy, noisy environments which may be inappropriate for people who need to avoid sensory over-load.

- Tasmanian Office of the Public Guardian

**Public sector employment targets and initiatives.**

- **Australian Public Service** 7% (by 2025) includes autism employment initiatives
- **Victorian Public Services** 12% (by 2025) includes autism employment initiatives such as the **RISE Program** and the Autism Success Network.
- **Tasmania’s State Service Diversity and Inclusion Policy and Framework 2017–2020** seeks to increase employment of people with disability in the State Service although it lacks targets or specific autism initiatives.

Ideas For Action

9. Embed autism responsive approaches into Job Tasmania initiatives. This should include autism measures in the youth focussed employment projects and community of practice, and the Regional Jobs Hubs network.
10. Pilot autism-focussed employment programs in a range of sectors and settings, including Tasmanian State Services.

**Key decision makers and Processes**

<b>Led by the Federal Minister for Disability</b>	<i>Development of National Autism Strategy Redesign of Disability Employment Services</i>
<b>Health and Mental Health Ministers</b>	<i>National Roadmap Health &amp; Mental Health for Autistic People</i>
<b>Tasmanian Minister for Skills, Training and Workforce Growth employment</b>	<i>Jobs Tasmania initiatives, including youth employment.</i>
<b>Tasmanian Minister for Education, Children &amp; Youth</b>	<i>Education reform policy.</i>

# Health and Mental Health

## Autistic people face stark health inequalities :

- *Life expectancy is 20-36 years shorter than the general population.*
- *The majority (50–70%) of Autistic people also experience mental health conditions, with depression, anxiety disorders, eating disorders, obsessive compulsive and bipolar disorders being common.*
- *Autistic burnout, often from masking behaviours (chronic exhaustion, skills regression, lower tolerance for stimuli).*
- *Suicide risk is up to 7 times higher than the general population.*
- *Autistic children and teenagers are 10 times more likely to have a hospital admission.*
- *Autistic children less likely to participate in sports and find refuge in extended screen time.*
- *Autistic mothers high rates of pre- and post-natal depression and lower rates of breastfeeding.*
- *Higher risk of dementia.*
- *Lower awareness of body signals (interoception) such as pain, temperature extremes and hunger.*

## Key Issues

- Low autism awareness and understanding is common amongst health and mental health workforces. This can lead to misdiagnosis, inappropriate treatments and damaging experiences.<sup>16</sup>
- Major care gaps for people with complex support needs or challenging behaviours.
- Health care environments frequently trigger sensory sensitivities of Autistic people.
- Autistic communication styles can serve as a barrier (including nonverbal, literal understandings etc).
- Long wait lists for psychology and mental health supports and lack of in-patient mental health beds.
- High out of pocket costs – including for Medicare rebated services such as psychology and allied health.
- Restrictive practices (chemical and physical restraint) are still in use.<sup>17</sup>

*Tasmania's Child and Adolescent Mental Health services has a practice of turning young people with autism away.*

- Autism Tasmania staff member

*My child's diet is very limited. He will only eat white foods.*

- Autism Tasmania community members

## Promising approaches

### National Health & Mental Health Roadmap for Autistic people

*The Disability Royal Commission found there is systemic neglect of Autistic needs in health services and called for a dedicated Roadmap. The Australian Government has commenced consultation and design work, which involves the Tasmanian Government and autism representatives.*

### WA Autism Health Project

*The WA Government and Autism Association of WA are working on project to improve access to healthcare for Autistic people (barriers, enablers, journey mapping, co-design, evaluation and training resources). It includes a pilot of specialist dental services.*

### Autism expertise in Victoria's new Child and Family Mental Health & Wellbeing Hubs

*As recommended by Victoria's Mental Health Royal Commission, new community hubs are being established for children and their families which will include autism capability.*



*Autistic people can experience a range of co-occurring health conditions which are either not known, are misunderstood or are poorly managed. This can result in poor health and, in some cases, potentially avoidable deaths.*

*Education providers are failing to consistently teach health care students about how to provide safe and quality healthcare for people with cognitive disability, with no specific requirements to teach about this topic.*

- Disability Royal Commission, Healthcare report

## Ideas For Action

11. Develop a Tasmanian Roadmap for Health & Mental Health for Autistic people to complement the national approach. It would focus on building autism responsiveness across state-led parts of the health and mental health system such as preventive, community health, maternal and child health and public hospitals. Tasmania's upcoming disability health plan and investment in building new health and mental health

The Senate Autism Inquiry recommended that the Australian Government work with state and territory governments and relevant stakeholders to encourage hospitals and public health care settings to adopt measures to improve the experience of Autistic people. Suggested measures included: providing guidance about reasonable adjustments; employing autism liaison officers; quiet spaces in hospitals and health care facilities; autism specialist mental health services and a strategy for autism training and professional development opportunities for health and mental health service professionals and staff.

## Key decision makers and Processes

**Led by the Federal Minister for Disability**

*Development of National Autism Strategy*

**Health and Mental Health Ministers**

*National Roadmap Health & Mental Health for Autistic People*

**Tasmanian Minister for Disability**

*Development of Tasmania's next state disability strategy (Accessible Island #2) and Tasmanian contribution to the National Autism Strategy.*

**Autism assessment providers**

*Implementation of National Autism Assessment Guideline*

**Tasmanian Minister for Health, Mental Health & Wellbeing**

*Mental health system reform  
Tasmania's contribution to National Health & Mental Health Roadmap for Autistic People  
Tasmania's disability health plan (consultations started)  
Planning for new (and upgraded) health and mental health infrastructure*

**Tasmanian Minister for Education, Children & Youth**

**Tasmanian Minister for Disability**

# Social and Community Inclusion

## Many Autistic people and their families experience extreme social isolation:

- *More than two thirds of Autistic people and parents/carers report feeling socially isolated.*
- *Almost half of Autistic adults sometimes feel unable to leave the house because they are worried about people behaving negatively towards them and most parents/carers also reporting this.*
- *41.4% of autistic adults experienced discrimination or stigma.*
- *Loneliness and feelings of exclusion negatively impacts mental health and wellbeing, and hinders engagement in sports, community life, study and work.*
- *The pandemic has exacerbated isolation for some.*

*Autistic children and their parents are often ostracised by society, even by people we know well.*

- Autism Alliance Community Survey 2020

## Key Issues

- Many Autistic people and their families are at risk of ongoing social isolation.
- Community attitudes, and the inclusiveness of clubs, groups and businesses is variable. Low understanding about autism is widespread.
- Crowds, noise, lighting, smells, colours, spatial features, flooring and other design elements can trigger sensory processing difficulties. It is common for Autistic people to avoid places because of sensory triggers.
- Access to (or lack of) information about a place is important. Non-verbal channels, signs, sensory maps and social stories enable preparation and reduce the unknowns.
- Tasmania's current disability accessibility initiatives respond to the needs of people with physical disability. They fail to cater for invisible or hidden disabilities.

*I am less isolated and have more things to do around Hobart thanks to the people I have met through Peer Support: the Autistic Way. Understand that when we interrupt, we are not rude. We cannot always judge timing in conversations.*

*I experience the unjust consequences of mainstream and community services that should by now be more knowledgeable and appreciative of Autistic people, their diverse strengths and needs.*

-Autism Tasmania community members

## Promising approaches

- Autism Tasmania's Open to Autism community education campaign launched late 2022 and included an initial series of posters and animations to build autism understanding. The Victorian Government has funded a paid media campaign, Change Your Reactions, to address community attitudes to autism. Evaluation results revealed positive impacts from this campaign.
- Peer networks play a crucial role in building connecting and bolstering Tasmania's autism community by offering a supportive and welcoming environment and strengthening capabilities as people learn from each other's experiences and insights.
- There are a range of peer support models, including:
  - Autism groups connected to Autism Tasmania (including groups for Autistic adults, parents and carers, and young people).
  - Groups connected to the Association of Children with Disabilities or Speak Out (where someone has co-occurring intellectual disabilities).
- A small number of organisations and businesses across Tasmania have taken steps to create autism friendly environments such as the Hawks Community Foundation (an Autism Tasmania partner) The team has undertaken autism training, and innovations, such as erecting a sensory tent at football matches and community events, creates a welcoming and safe environment.

### **National Assistance Card Autism Trial (Tas).**

The National Assistance Card (initially designed for people with brain injury) has recently been expanded to Tasmania's Autistic community. It is designed to make it easier for people to communicate their unique needs for understanding or assistance, to encourage greater participation and to build broader community understanding of autism. A lived experience Autism Trial Advisory Group tailored the National Assistance Card to meet the needs of the Autistic community.

### **Gold Coast Airport's Hidden Disability Scheme**

In partnership with Autism Spectrum Australia, Gold Coast Airport has implemented a comprehensive assessment based '**Hidden Disabilities**' scheme that includes a range of web-based resources to aid preparation and predictability for Autistic people and their families, on-site sensory accommodations and extensive staff training. Significantly, this has led to the creation of Hidden Disability resources for the Australian Airports Association.

## **Ideas For Action**

12. Create more autism accessible events, venues and environments.

- Refresh the Tasmanian Governments Accessible Event Guidelines to address autism accessibility considerations (such as sensory mapping, social scripts and quiet spaces). The current Guidelines are almost exclusively focussed on physical disability.
- Position the Tasmanian Government as an exemplar in autism-friendly environments across state venues. Incentivise business, community, sports and arts organisations to do the same.

13. Partner with community organisations to extend the reach and impact of Autistic peer support, including for groups at higher risk of marginalisation (including females, culturally and linguistically diverse, First Nations and LGBTQIA+ people).

## **Key decision makers and Processes**

**Led by the Federal Minister for Disability**

*Development of National Autism Strategy*

**Tasmanian Minister for Health, Mental Health & Wellbeing**

*Development of Tasmania's next state disability strategy (Accessible Island #2)*

**Tasmanian Minister for Tourism, Tasmanian Minister for Disability, Tasmanian Minister for Transport, Tasmanian Minister for the Arts, Tasmanian Minister Hospitality & Events, Tasmanian Minister Hospitality & Events, Tasmanian Minister Sport & Recreation, and the Tasmanian Minister for Disability**

*Tasmanian contribution to the National Autism Strategy. Autism friendly events, venues and environments.*

# Rights and Advocacy

Autism-responsive advocacy support (for self, individual and systemic advocacy) is critical for:

- Building community capability.
- Enabling Autistic people and their families to access and navigate key service systems without discrimination and ensuring their rights are upheld.
- Bringing together the diverse views and perspectives of the Autistic community.
- Ensuring Autistic voices and experience inform policy and decision makers.

- Providing ways for systemic issues to be identified and reported to inform good programs, policy and practice responses.

*Without state investment in dedicated autism advocacy and representation, Tasmania's Autistic community are at risk of being disadvantaged in major national and state reform processes underway.*

- Australian Autism Alliance 2023

- 45% of Autistic adults and families/carers of Autistic people do not know where to get help if experiencing discrimination (in education, accommodation, recreation and leisure).
- More than 22% of Autistic adults report not knowing where to get help if experiencing violence, abuse or neglect.
- 77% of the general population agree that Autistic people are discriminated against.

## Key Issues

- Autism perspectives are under-represented on government and community-based inclusion and disability advisory groups. The Tasmanian Government currently has no autism-specific advisory groups.
- Autistic people often experience barriers in accessing general advocacy services, and such services can lack the understanding and approaches needed. The Senate Inquiry into Autism called for States to support autism-specific advocacy services.
- No autism specific advocacy services (systemic, individual or self-advocacy) are funded in Tasmania, despite the size of the Autistic population and the poor outcomes relative to other disability groups.
- Speak Out's advocacy service, although focussed on people with Intellectual Disability, has many clients with co-occurring autism.
- Autistic clients (children and their families) comprise a significant proportion of ACD's advocacy client base.
- Autistic people have featured heavily in evidence given to the Disability Royal Commission, indicating higher vulnerability to violence, abuse, neglect and exploitation.

*Sufficient capacity and sustainability of advocacy supports for people with autism is critical to ensure the basic tenets of the NDIS, choice and control, are met.*

- Tasmanian Office of the Public Guardian Senate Autism Inquiry Submission 2020

*State and territory government should commit to funding autism-specific advocacy services as part of their disability advocacy programs.*

- Senate Inquiry into Autism 2022

## Promising approaches

- The Tasmanian Autism Diagnostic Service (TADS) was commended by the Senate Autism Inquiry as a good example of an effective interface between government agencies (education and health).
- Although in the mental health area, *Flourish* is an exemplar Tasmanian model that could be replicated for autism. Flourish's Consumer Representative Service (CRS), established with Tasmanian government funding, supports the meaningful participation of people with lived experience in decision-making forums such as working groups and committees relevant to mental health. Flourish provides training, mentoring and support for their consumer representatives. This work is also used to inform understanding of systemic issues.
- The Premier's *Disability Advisory Council* has a high profile. It meets regularly with Tasmanian Government Heads of Agencies to discuss issues and monitor agency progress on implementation of Accessible Island. Autism does not appear to currently be represented on this important committee.

*Victoria has several autism specific advisory groups including:*

- *An Autism Advisory Group to advise on implementation of the Victorian Autism Plan.*
- *An Autism Education Advisory Group.*
- *An autism and mental health collaboration.*

*Autism representation is also explicitly included in the membership of key generic disability and inclusion advisory groups. Systemic advocacy and participation is supported by multiple state government departments.*

## Ideas For Action

14. Ensure Autistic people and their organisations are represented on key state and local government disability/inclusion advisory committees, and national autism reform processes. Use Tasmania's Flourish (mental health consumers) model as a model for enabling and building capability for lived experience participation.
15. Support dedicated autism advocacy – systemic, individual and self-advocacy – to amplify the experiences and advance the rights of Autistic Tasmanians.

## Key decision makers and Processes

**Led by the Federal Minister for Disability**

*Development of National Autism Strategy*

**Health and Mental Health Ministers**

*National Roadmap Health & Mental Health for Autistic People*

**Tasmanian Minister for Disability**

*Development of Tasmania's next state disability strategy (Accessible Island #2) and Tasmanian contribution to the National Autism Strategy.*

**Premier of Tasmania**

*Premiers Disability Advisory Council*

# Housing

- *People with disability are eight times more likely to live in public housing.*
- *A small portion of NDIS participants receive funded housing supports*
  - *Supported Disability Accommodation (SDA) funds specially designed/modified accommodation (independent or shared) for people with extreme functional impairment or very high support needs. SDA stock is mostly owned by the State Government, who then head-leases to NDIS registered housing and support providers, who in turn let it to NDIS participants.*
  - *Supported Independent Living (SIL) funds daily services and supports (from regular supervision to round the clock care) to assist those who cannot live independently without it. SIL is being reviewed as part of the NDIS reboot.*

Autism-specific housing challenges sit at the intersection of disability, housing and homelessness, and consumer affairs policy. They crosscut all levels of governments.

These challenges are in addition to the broader affordable housing shortages facing Tasmanians more generally (including long social housing wait lists, lack of affordable rentals and high house prices).

*Children leaving institutional care are disproportionately represented in homelessness statistics...*

*Some young people with disability who are unable to live in the family home because of their complex disability support needs can face significant challenges finding safe, stable accommodation appropriate to their needs.*

*- Under 16 Homelessness Tasmanian Policy Framework*

## Key Issues

- There is little housing stock available that suits families with children with challenging behaviours.
- Despite aspirations to choose where and with whom they live, Autistic people (particularly those with complex behaviour or intellectual disability) receiving home and living supports via the NDIS often have little choice but to live in supported group (congregate) housing. Segregated from the broader community, residents' protections and rights can be precarious, particularly when beholden to a provider that is both their landlord and service provider.
- There is a lack of 'robust' housing in public/social housing stock, emergency respite and SDA stock. The 'robust' category of housing design is intended to reduce the risk of injury for people with complex behaviours and those that live with or visit them and to minimise neighbourhood disturbance. It incorporates resilient materials designed to cope with heavy use, safety features and soundproofing. Construction of this very specific accommodation response is typically not attractive to the market and thus largely falls on state governments to plan for.
- Autistic adults frequently remain living in their parents/carers home, impacting independence and parent/carer roles.
- Autistic people face increased risk of homelessness given their overrepresentation in out-of-home care and the justice system.

*Well-designed housing in the right location can allow for more independent living arrangements, increased community connection and access to informal supports.*

*The absence of appropriate housing can result in people with autism requiring hospitalisation for safe accommodation rather than any medical need.*

- NDIS website



## Promising approaches

- The upcoming NDIS ‘reboot’ includes an overhaul of Supported Independent Living with the intent of enabling participants greater choice and control over living arrangements, including for those wanting to move away from group/congregate housing.
- The SDA Pricing Review underway intends to drive market investment in innovative specialist disability design housing. Increased price caps should support an increasing supply of ‘robust’ housing.
- The current Action Plan under Tasmania’s Affordable Housing Strategy 2015 - 25 includes funded commitments to construct new homes that are purpose built for NDIS participants with complex and exceptional needs who require a tailored form of integrated housing and support. This creates opportunity to expand the robust housing stock.
- This could be ‘turbo-charged’ by the:
  - **National Housing Accord**, which involves all levels of government working with superannuation funds, other investors and community organisations to expand the supply and affordability of housing.
  - Recent commitment by the Disability Ministers Council to: work together to increase supply of safe, affordable and accessible housing for people with disability; and work with their Housing counterparts and task housing and disability senior officials to scope a program of joint work to deliver improved housing outcomes for people with disability<sup>18</sup>
- Tasmania’s youth homelessness approach<sup>19</sup> commits to preventative action, including for young people with disability. It is unclear about the extent to which this work is autism informed.

## Ideas For Action

2. Reduce public waiting lists to no more than three months for children needing autism assessment and diagnosis.
3. Ensure robust and consistent approaches to assessing autism across Tasmania, based on the National Guideline, using TADS as an exemplar.

### Improving tenancy rights

*To strengthen the rights and safeguarding of people with disability, Victoria has brought **Supported Disability Accommodation** tenancies under their Residential Tenancies Act. To date, it is the only state to do so.*

## Key decision makers and Processes

### Housing Ministers (across Australia)

*National Housing Accord, National Housing & Homelessness Agreement (due for re-negotiation)  
Funding boost for public housing*

### Tasmanian Minister for Housing

*Overseeing implementation of Tasmania’s Affordable Housing Strategy*

### Tasmanian Minister for Youth

*Overseeing Tasmania’s U16 Homelessness Plan*

### Disability Ministers (across Australia)

*Commitment to working together to expand supply of affordable and accessible housing for people with disability*

### Tasmanian Minister for Disability

*Developing Tasmania’s new Disability Plan*

### Minister for the NDIS

*Reviewing Supported Independent Living*

### NDIS Quality & Safeguarding Commission

*Implementation of action plan following their Own Motion Inquiry into aspects of Supported Accommodation in January 2023.*

# Justice

Autistic people interact with the justice system at comparatively high rates as both victims and those accused of crime.

The Autistic community are at higher risk of having negative and potentially traumatising encounters with the criminal justice system.<sup>20</sup>

*While behavioural or developmental concerns may be well recognised in a young person and appropriate paediatric referrals made – they still may not be assessed for up to 24 months.*

*Left waiting and unsupported, these children and young people are more likely to come to harm, and exhibit their distress through escalating antisocial behaviour, with long term and sometimes lifelong consequences.*

- Tasmanian Draft Youth Justice Blueprint 2022.

*People with developmental disabilities are overrepresented in family violence and sexual abuse (seven times higher) and are particularly vulnerable to abuse and neglect.*

*Of the Autistic adults that responded to the 2020 Autism Alliance Community Survey:*

- *Over one-third reported that they had been involved in the criminal justice system (as a victim, witness or accused).*
- *Two-thirds rated the knowledge and understanding of autism across police, courts and prisons as poor.*

## Key Issues

- Some Autistic people have traits that may increase their vulnerability to criminal involvement: challenges with cognitive processing and reading social cues; communication differences; emotional regulation difficulties; trusting natures that can be taken advantage of; and co-occurring mental ill health.
- Many Autistic people remain undiagnosed, or misdiagnosed, and do not have supports in place.
- There is limited understanding of autism across the justice workforce and a lack of appropriate adjustments made to support Autistic victims, witnesses and accused.
- There have been significant gaps in the interface between NDIS supports and people intersecting with the justice system. The more recent NDIS Justice Liaison Officers and reforms to the Complex Needs Support Pathway presents an opportunity to address this, including through prevention and early intervention.

## Promising approaches

- Tasmania's upcoming [\*youth justice reforms\*](#)<sup>21</sup> include a specific focus on improving support for young people with cognitive impairment, and for people with disability more generally. A public health approach, focussed on prevention, early intervention, diversion and therapeutic model of custody (in purpose-built facilities) is planned.
- Actions anticipated to follow [\*Tasmania's Commission of Inquiry into Child Sex Abuse\*](#)<sup>22</sup> will focus on increasing safety in institutional settings and out-of-home care (which have an over-representation of Autistic children and young people.)



*The **Developmental Disabilities Justice Toolkit**, which is a Canadian resource comprising information and advice for justice staff (police, courts, prison staff). It addresses communication, interviewing strategies, challenging behaviours, special considerations in a range of settings and practical fact sheets.*

*The **Be Safe Resource Collection**, which is aimed at preventing sexual abuse and assaults in individuals with autism, including children. There are resources for Autistic people, incorporating social stories and resources aimed at caregivers and professionals. The series was produced by the Autism Services, Education, Resources, and Training Collaborative with support from the state government of Pennsylvania (USA).*

## Ideas For Action

18. Develop guidance, tools and training to equip the justice system and workforce to better support the specific needs of Autistic victims, witnesses, accused/perpetrators.

19. Ensure the increased risk factors experienced by Autistic people are specifically addressed in future responses to sexual abuse.

20. Support cognitive assessment and NDIS eligibility screening for people interacting with the justice system displaying developmental or complex behavioural concerns.

## Key decision makers and Processes

**Tasmanian Minister for Prevention of Family Violence**

*Overseeing implementation of Tasmania's Family and Sexual Violence Action Plan 2022-27*

**Tasmanian Minister for Education, Children and Youth**

*Youth Justice reforms.*

*Commission of Inquiry into Tasmanian Government responses to Child Sexual Abuse in Institutional Settings.*

**Tasmanian Minister for Justice**

*Refresh of Disability Justice Plan 2017-20*

**Tasmanian Minister for Police, Fire and Emergency Management**

*Refresh of Disability Justice Plan 2017-20*

**Tasmanian Minister for Disability**

*Development of Tasmania's next state disability strategy (Accessible Island #2)*

*Tasmanian contribution to the National Autism Strategy.*

**Federal Attorney-General and Minister for Home Affairs**

**Federal Police and Federal Courts**

# Attachment 1:

## Impending policy changes that will affect Autistic Tasmanians

### National Autism Strategy (NAS)

#### National perspective

*Recommended by the Senate Inquiry into Autism, the upcoming National Autism Strategy is intended to drive comprehensive and coordinated efforts to improve whole of life outcomes for all Autistic people. It will include consideration of guidelines on autism-friendly service design, community education and an autism workforce plan. The Autism Strategy will have accountabilities, targets, actions and milestones that will align with the Australian Disability Strategy. A national consultation and co-design process will be guided by an Oversight Council and Working Groups representing autism interests, including Autistic people and their families and carers.*

#### Tasmanian perspective / implications

*Priorities in the upcoming National Autism Strategy and how they are funded and implemented may significantly impact the lives and experiences of Autistic Tasmanians. Because the Strategy will cover areas that cross roles and responsibilities of different levels of government, Tasmania's active collaboration in developing and implementing the Strategy will be critical to its success. Some States (Victoria and South Australia) have existing State Autism Plans which will likely be updated to complement and support delivery of the national strategy. It is anticipated other states may develop their own targeted state plans.*

#### Timelines

*Work has commenced. Working groups have been appointed.*

**Expected release mid-2025.**

### National Autism Strategy focus outcome areas:

#### Economic Inclusion

- Choice and opportunity in education and learning.
- Transition from secondary education to tertiary education and employment.
- Increase employment and employment options.
- Strengthen financial independence and security
- Accessible transport of choice.

#### Diagnosis, Supports and Services

- Adequacy of and access to services and supports.
- Improve service integration, coordination and pathways.
- Assessment and diagnosis.
- Early intervention supports.
- Advocacy services.
- Supporting families and carers.
- Inclusive and accessible housing / accommodation.
- Choice and control when accessing services.
- Research, data and measurement to support continuing improvement.

#### Health and Mental Health

- Best practice models of care.
- Support to navigate the health system.
- Education and training of health professionals.
- Improved coordination of health, mental health supports and other sectors.
- Research, data and measurement to support continuing improvement.

#### Social Inclusion

- Promote, uphold and protect safety, rights and justice.
- Build inclusive communities.
- Build understanding and acceptance of autism within wider community.
- Access to personal and community services and supports.
- Accessible information and communication systems.
- Housing and accommodation.

## National Roadmap Health & Mental Health

### National perspective

A dedicated national roadmap for health and mental health of Autistic people is being developed in tandem with the National Autism Strategy. Called for by the Disability Royal Commission and the Senate Inquiry into Autism, it is inspired by the existing health roadmap for people with intellectual disability.

### Tasmanian perspective / implications

Strengthening health and mental health supports (such as GPs, allied health, hospitals, aged care) to better understand and meet the needs of Autistic Tasmanians should make a positive difference. The Tasmanian Government will be a significant partner in delivering this Roadmap given its responsibility for key parts of the health and mental health system. They are represented on the Working Group.

### Timelines

Work has commenced. Working groups have been appointed.

**Expected release mid-2025.**

## NDIS Reforms

### National perspective

A major NDIS Review is underway. Review objectives are: putting people with disability back at the centre of the NDIS; restoring, trust, confidence and pride in the NDIS; and ensuring sustainability of the scheme so that future generations receive the benefit of the NDIS.

NDIS Minister Bill Shorten has emphasised the need for the NDIS to return to its original purpose of serving people with the most severe impairments and profound disabilities. He has outlined the following directions for the upcoming “NDIS Reboot:”

- 1.Strengthening the capability and culture of the NDIA and its workforce.

- 2.Moving to longer term individual NDIS plans.

- 3.Containing spiralling costs by ensuring evidence based, cost-effective supports that provide maximum benefits and value to NDIS participants.

- 4.Reviewing Supported Independent Living to enable more innovative housing models.

- 5.Eliminating the misuse of funds including tackling unethical provider practices and ‘shoddy’ therapies.

- 6.Strengthening the inclusion of community supports and mainstream services.

### Tasmanian perspective / implications

Outcomes of the NDIS review will heavily impact Tasmania’s Autistic community given their high participation in the scheme. Autism is the most prevalent disability among Tasmanians receiving NDIS supports (35% of record autism as their primary or secondary disability).

Around 90% of Autistic Tasmanians receiving NDIS support are under 25 years old and approximately two-thirds of 7–18-year-olds on the NDIS are Autistic.

Strengthened focus on evidence-based supports could also impact what the NDIS will fund. Pricing and purchasing approaches are expected to be changed – particularly in Tasmania given its thin markets and regional status.

State and local governments, business and community are expected to play a stronger role in creating inclusive environments and providing supports outside of the NDIS.

### Timelines

Consultations underway. The Disability Ministerial Council is being regularly briefed on the Review. Review report **due October 2023.**

Implementation of some changes have commenced (fraud taskforce, NDIA staffing).

## Community Supports

### National perspective

*Improving supports available for all people with disability, regardless of whether they have an individual NDIS plan, has been identified as a national priority and is a focus of inter-governmental negotiations. Reforms to the national Information Linkages and Capacity Building (ILC) program are expected to be announced later in 2023. The program provides grant funding to organisations to deliver projects in the community that benefit people with disability. There is significant scope to improve it.*

### Tasmanian perspective / implications

*There is significant national pressure on states to increase their investment in disability support. As the NDIS was rolled out, the Tasmanian Government (and other States) reduced their delivery and funding of other (non-NDIS) supports for people with disability. A recent Tasmanian Legislative Council Inquiry found that there are significant gaps and shortfalls for those not receiving NDIS supports. The Tasmanian Government has yet to publish a response to the Inquiry's recommendations. The next version of the national ILC program is important to Autistic Tasmanians, with Autism Tasmania's operations currently reliant on this funding. While there are a range of other disability supports and inclusion initiatives funded by the ILC for Tasmanian coverage, there appears to be little engagement of Autistic Tasmanians in these.*

### Timelines

*Outcomes of ILC Review due **October 2023**. Inter-governmental negotiations on community and mainstream supports **Ongoing**.*

## Mainstream Services

### National perspective

*The inclusiveness of mainstream services (health, mental health, early childhood and family support, schools, TAFE/training and universities, employment, housing and community infrastructure, transport and justice) is an area of increased attention. The interface of NDIS support and mainstream services remains problematic and is often unclear. Minister Shorten is particularly calling for schools and the mental health system to better cater to all people with disability rather than placing over-reliance on the NDIS.*

### Tasmanian perspective / implications

*The responsiveness and inclusion of mainstream services for Autistic Tasmanians is heavily dependent the Tasmanian Government policy, programs and practices.*

### Timelines

*Inter-governmental negotiations on community and mainstream supports **Ongoing**.*

## Australian Disability Strategy (2021-31)

### National perspective

Renewed in 2021, this national strategy seeks to drive improved outcomes for people with disability across the areas of Employment and Financial Security; Inclusive Homes and Communities; Safety, Rights and Justice; Personal and Community Support; Education and Learning; Health and Wellbeing; and Community Attitudes. State and Territory disability plans need to align with the Strategy. The Disability Ministers Council will drive collaboration across governments to implement, measure and report on outcomes under the Strategy. Creation of the National Disability Data Asset is a foundational element. It aims to link different government data sets to give a more complete picture of the life experiences of people with disability. A pilot has been completed and work is underway for incremental roll out, with an initial focus on health, employment and early childhood data.

### Tasmanian perspective / implications

Renewed in 2021, this national strategy seeks to drive improved outcomes for people with disability across the areas of Employment and Financial Security; Inclusive Homes and Communities; Safety, Rights and Justice; Personal and Community Support; Education and Learning; Health and Wellbeing; and Community Attitudes. State and Territory disability plans need to align with the Strategy. The Disability Ministers Council will drive collaboration across governments to implement, measure and report on outcomes under the Strategy. Creation of the National Disability Data Asset is a foundational element. It aims to link different government data sets to give a more complete picture of the life experiences of people with disability. A pilot has been completed and work is underway for incremental roll out, with an initial focus on health, employment and early childhood data.

### Timelines

Ongoing. Targeted Action Plans are being incrementally developed and implemented. State companion Disability Strategies are being developed.

**Work is soon to commence on Tasmania's state disability strategy.**

## Disability Royal Commission

### National perspective

Australia's Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability has been running since 2019. Its final report is due by late 2023 and is expected to drive substantial systemic reforms which should be particularly relevant for the Autistic community who experience high levels of discrimination, violence, abuse and neglect. It has already made some interim findings and recommendations relating to people with cognitive impairment, Including autism. The Australian Disability Strategy is scheduled to be reviewed following the final report of the Disability Royal Commission.

### Tasmanian perspective / implications

Many of the Royal Commissions findings and recommendations will relate to policy, services, programs, practices and safeguards that impact Autistic Tasmanians. The Royal Commission is expected to prompt action by the Tasmanian Government and its agencies, as well as Tasmanian service providers and community organisations.

### Timelines

A series of reports and hearing summaries have been issued. Hearings and submission have finished. **Final report due October 2023**

## National Early Years Strategy

### National perspective

A national Early Years Strategy focused on children in the first five years of life and their families is currently being developed and will need to align with the Australian Disability Strategy and the upcoming National Autism Strategy.

The Strategy will guide Australian Government policy and actions over the next decade in areas such as:

- universal supports such as parental leave and childcare subsidies
- contributions to maternal child health and preschool (delivered by states)
- targeted support for families and children who face additional challenges, including disability (such as supported playgroups, parental supports and the non-ended autism Early Days workshops.)
- family violence supports.

The Productivity Commission is also commencing an inquiry into universal, affordable early education and care, with special attention for families experiencing disadvantage and children with disability.

### Tasmanian perspective / implications

Collaboration between different levels of government will be critical to the upcoming national Early Years Strategy.

Tasmania's It Takes a Tasmanian Village' Child and Youth Wellbeing Strategy has significant focus on the first 1000 days and commits to a focus on children with disability.

The roll out of universal pre-school for 3-year olds in Tasmania is also closely interlinked

### Timelines

Consultations underway.

**Anticipated late 2023**

## Employment Reforms

### National perspective

The current Disability Employment Services (DES) program will be replaced by a new specialist disability employment program from mid-2025. Design details are yet to be released.

The Disability Discrimination Commissioner has launched IncludeAbility to support employers and people with disability with employment.

### Tasmanian perspective / implications

The Tasmanian Government has a strong focus on employment, including addressing skills and labour shortages.

Jobs Tasmania has established regional jobs hubs and has a significant focus on the successful transitions of young people into employment (as part of the broader Youth Wellbeing Strategy). There is a commitment for these new initiatives to be inclusive.

### Timelines

**New DES program Commences mid-2025**

## Education Reforms

### National perspective

*The Disability Standards for Education (DSE) provide that students with disability have the right to equality of access to education and require educational institutions to provide reasonable adjustments.*

- *National efforts to strengthen implementation of the DSE's (following a **recent review**) include a focus on: empowering and supporting students with disability and their families; strengthening the knowledge and capability of educators and providers; embedding accountability for the Standards throughout the education system; and building awareness and capability in the early childhood education and care sector.*
- *Recommendations of the Senate Autism Inquiry included developing an "Autism Lens" in implementing the recommendations of the DSE review.*

### Tasmanian perspective / implications

*The Tasmanian Government is responsible for implementing the DSEs in those parts of the education system it administers including pre-school/kindergarten, schools and TAFE. Tasmania is rolling out universal pre-school for three-year olds and is also expanding senior secondary school options.*

### Timelines

**Ongoing**



# Endnotes

<sup>1</sup> The most recent ABS statistics (2018) revealed that 3.2% of children aged 5-14 years and 1.1% of 15 – 40-year-olds have an autism diagnosis. Overall, 1.3% of males and 0.4% of females have an autism diagnosis. Barriers to diagnosis mean that actual prevalence is likely to be much higher. The apparent higher incidence in younger age groups reflects lower rates of diagnosis among adults. Upcoming ABS statistics (to be released in 2024) are anticipated to reveal a significantly higher rate.

<sup>2</sup>Includes immediate and extended family members ACU, Amaze, SRC, 2022. Autism Inclusion Monitor (publication forthcoming).

<sup>3</sup>From ECEI data cited in the Tasmanians Government's submission to the Senate Autism Inquiry 2020

<sup>4</sup>Australian Autism Alliance, *The Autism Dividend: Unleashing the skills, talent and opportunity of Australia's autistic community*, Submission to the Senate Select Committee on Autism, Aug 2020. Citing results of the Autism Community Survey.

<sup>5</sup>TADs received 480 referrals in 2019 (a steady increase from 173 referrals in 2011) which has resulted in lengthy wait times. This is largely attributed to roll-out of the NDIS and also DoE Educational Adjustment funding which is based on diagnosis. Around half of those currently assessed by TADs are given an autism diagnosis.

<sup>6</sup>Lilley, Sedgwick & Pellicano, *We look after our own mob: Aboriginal and Torres Strait Islander Experiences of Autism*. Macquarie University: Sydney (2019).

<sup>7</sup>Parliament of Tasmania, Legislative Council Government Administration Committee "B" Report on Disability Services In Tasmania, 2022

<sup>8</sup>National Aboriginal Community Controlled Health Organisation, Select Committee on Autism Submission, Aug 2020.

<sup>9</sup>Such as the Parenting Resource Centre's MyTime

<sup>10</sup>Tasmanian Government, *Child And Youth Wellbeing Strategy "It takes a Tasmanian Village" Annual Report 2022*

<sup>11</sup>Tasmania has around 200 government schools catering to over 63,000 students, (check). While there are no accurate figures on the number of Autistic students, in 2019 there were over 1,000 school students known to the (former) Autism Consultants.

<sup>12</sup>DoE data shows that as at December 2019, 39 students with autism are in the mid extensive range; 84 in low extensive; 141 in high substantial; 155 in low substantial; 195 in supplementary; and 229 in Quality Differentiated Teaching Practice. (Nationally Consistent Collection of Data (NCCD) levels).

<sup>13</sup>The Positive Partnerships program provides professional development for teachers, principals and other school staff to build their understanding, skills and expertise in working with autistic school-age students. It provides workshops, information sessions, and other online resources for parents and carers of autistic school-age students.

<sup>14</sup>Education Services Australia has been engaged by the Australian Government to expand the autism-specific resources and case studies (on the web portal for the Nationally Consistent Collection of Data on School Students with Disability).



<sup>15</sup>Robert Austin and Gary Pisano, *Neurodiversity as a Competitive Advantage*, *Harvard Business Review*, 2017

<sup>16</sup>Recommendations from the 2021 Australasian Society for Autism Research “Health, Wellbeing and Suicide Prevention in Autism” Conference and Roundtable May 2022

<sup>17</sup>The Australian Disability Strategy advances commitments under the United Nations Convention on the Rights of Persons with Disabilities to reduce and eliminate the use of restrictive practices.

<sup>18</sup>Disability Reform Ministerial Council, *Communiqué*, Brisbane 21 April 2023,

<sup>19</sup>Tasmanian Government, *Under 16 Homelessness Children and young people under 16 who are alone and at risk of or experiencing homelessness: A Policy Framework for Tasmania*.

<sup>20</sup>International Society for Autism Research, *Autism and the Criminal Justice System: Policy Opportunities and Challenges*, Policy Brief, April 2022. A project of the Global Autism and Justice Consortium.

<sup>21</sup>Tasmanian Government, Department of Education, Children and Young People, *Youth Justice Blueprint 2022 Building a connected and responsive youth justice system, Final Draft as of November 2022*

<sup>22</sup>Commission of Inquiry into the Tasmanian Government’s Responses to Child Sexual Abuse in Institutional Settings is due to report August 2023.

# About Autism Tasmania

Established over thirty years ago by Autistic people and their families, [Autism Tasmania](#) is the peak independent voice for the Tasmanian autism community.

Autism Tasmania has a dedicated team of staff and volunteers, many with lived experience as Autistic individuals or family members. We are governed by a highly committed, Autistic-led Board, who are supported by an Autistic Advisory Group and a Parents, Friends and Loved Ones Advisory Group. Autism Tasmania has a large community of over 3000 members, many of whom are connected with us across their lives.

We are deeply embedded in the autism community through our advice line, our [regular drop-in sessions](#), our grassroots network of peer groups all over the state, our NDIS support co-ordination, and our events and training. Our recent Open to Autism community education campaign has reached many Tasmanians. Autism Tasmania strives for equitable social, economic and life opportunities for Autistic Tasmanians.

Our mission is to create the right conditions for Autistic Tasmanians to achieve and to grow community knowledge about autism and how to make a difference.

## About Autism

Autism is a highly prevalent and lifelong condition associated with brain development that affects the way people experience, sense, communicate, behave and interact with the world. It affects people from all backgrounds, cultures and faiths. Between 2-3% of the population are likely to be Autistic. Autism is experienced to different degrees and in varied ways. Each Autistic person has unique strengths, interests, potential, challenges and needs.

While many Autistic people require significant support with daily living, not all people impacted by autism identify as having a disability. Autism frequently co-occurs with other conditions, notably ADHD, dyslexia, epilepsy and intellectual disability. Around 50-70% of Autistic people also have a mental health condition.

## Autism Terminology

The language used to describe autism is important. Many different preferences are evident and expressed by Autistic Tasmanians and their loved ones. No single terminology preference is right or wrong. It is respectful to follow an individual's lead on how they would like to be referred to (for example: Autistic, person on the Autism spectrum, person with Autism, person with ASD, person with Asperger's/Asperger's Syndrome). For more information see [Autism Tasmania's Position Statement on Autism Terminology](#).

## Autism Tasmania's Core Values

### Inherent worth:

Autistic people are valuable members of society, capable of contributing to and enriching the lives of those around them.

### Social justice:

Some people need a greater share of resources to have equal opportunity.

### Individual dignity:

We value individuality and choice and believe that everyone should be treated with respect.

### Respecting language and identity:

Individuals have the right to choose the autism-related language that they believe most powerfully represents them.

### Evidence-based:

We value research and practice evidence and also use input from the autism community to inform better outcomes.

### Collaboration and community:

We value partnerships and celebrate the diversity and achievements of our community.

### Professionalism and accountability:

We operate transparently and with the best interests of our members and the Tasmanian autism community in mind.

# Affirming Neurodiversity

**Autism Tasmania works to be the exemplar organisation and to lead Tasmanians toward uniform, universal adoption of neuroaffirming conduct.**

Neurodiversity describes the idea that people experience and interact with the world around them in many different ways; there is no one "right" way of thinking, learning, and behaving, and differences are not viewed as deficits.

By adopting the principles of neurodiversity affirming (neuroaffirming) we will increase acceptance and inclusion of all people while embracing neurological differences.

The 11 core principles are:

Intersectionality

Respecting Autonomy

Validating Differences

Presuming Competence

Reframing Expectations

Promoting Self-Advocacy

Rejecting Neuronormativity

Prioritising Lived Experience

Nurturing Positive Self-Identity

Adapting Systems and Environments

Honouring All Forms of Communication

“Neurodiversity Affirming Practice: Core Principles” WISE, Sonny Jane. May 2023.  
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