

# Opportunity Autism

## Next Steps for Victorian Autism Policy

June 2022



# “We’ve come a long way, but have much, much further to go.”

- Autistic respondent, Autism Inclusion Monitor

Autism is a neurodevelopmental condition that affects the way people communicate and interact with the world. People are born Autistic, and it is a life-long disability. Autism affects many Victorians, from all walks of life.

- 3.2% of Victorian school students have an Autism diagnosis<sup>1</sup>
- Over 1 in 4 people have an Autistic family member<sup>2</sup>
- Over 74% of people know someone who is Autistic<sup>3</sup>
- Over 1 in 3 NDIS participants are Autistic<sup>4</sup>

**As a whole, the Autistic population experience very poor life outcomes – but with the right supports this can change.**

Whether in education, employment, mental health, life expectancy, health, or social and community life – Autistic people consistently have among the worst outcomes compared with other disability and vulnerable population groups. These dire outcomes come at huge cost to Autistic people, their families and the broader Victorian community.



**91% of Australians believe we need to find better ways to support Autistic people<sup>5</sup>**

With the right settings and supports, there is a huge opportunity to shift the dial on these outcomes and unlock the breadth of talent, ambition and skills of Autistic Victorians. While recognising and celebrating the advances Victoria has made in policy and program settings for Autistic people and their families over recent years, there is still much more to do.

As we emerge from the COVID-19 pandemic, it is in the interests of all Victorians to tap into Autistic potential to ensure this sizable community is not caught in a long tail of additional post-COVID disadvantage. The following actions represent key priorities for all political parties to support.

# Timely and affordable access to quality Autism assessment and diagnosis

## 1. Increase the proportion of Autistic children assessed and diagnosed by age 3 by building workforce expertise and health system capacity to undertake early diagnoses

Age of diagnosis matters. Autism can be detected very early, often in the first few years of life. Differences in outcomes for children diagnosed by age 2 compared with those diagnosed after age 3 can be stark because of the critical early window when a child's developing brain is highly malleable. Figure 1 (from the Olga Tennison Autism Research Centre) highlights the impact that even a short delay in diagnosis can make in terms of intellectual capacity and participation in mainstream schooling.<sup>6</sup>

Diagnosis by 24 months	Diagnosis between 3-5 years
8% have an intellectual disability	24% have an intellectual disability
77% in mainstream schools	57% in mainstream schools

Figure 1- Effects of early diagnosis \*(IQ < 70) at school age

While many people are diagnosed later in life, Victorian research indicates that we could more than triple the diagnosis rates for children aged up to 3 (from 20% to 70%) by building workforce skills and expertise (rather than the prevailing "wait and see" approach).<sup>7</sup> Maternal and Child Health nurses have been trained in early identification, however corresponding early diagnosis capability amongst clinicians and those undertaking the assessments is needed – including capability for early diagnosis of Autistic girls.

To address the long wait times for diagnosis (often 1-2 years) that currently exist, capacity needs to be expanded in Victoria's public and community health settings. The soon to be established Infant, Child and Family Mental Health and Wellbeing Hubs will provide autism assessments. It is critical they are equipped with the necessary early diagnostic skills as well as having capacity for rapid assessments to avoid delayed diagnoses.

## 2. Provide rapid and affordable access to autism assessments for young people and adults, including through Victoria's Mental Health & Wellbeing Hubs

Most Autistic adults are undiagnosed. Surveys highlight advantages of receiving a diagnosis at any age<sup>8</sup> with people saying that it:

- Helped me understand myself and helped me deal with feelings of being different/inadequate
- Helped give me a sense of belonging
- Helped me understand my needs and to explain my needs to others
- Helped me find ways to improve my life/situation
- Allowed me to access supports
- Gave me the confidence to disclose my autism.

Access to autism assessments and diagnosis for teenagers and adults has been long neglected, with negative impacts for mental health, relationships, education, and employment outcomes. Girls and women are particularly affected, as they are more likely to be diagnosed later in life.

Prohibitive assessment costs (more than \$2000), long wait lists and workforce capability are significant barriers to diagnosis. A small-scale 12-month pilot of autism assessments in some Victorian tertiary mental health settings commenced in 2021 and is proving effective in addressing the diagnostic and mental health needs of Autistic adults who were previously undiagnosed. There is a strong case for embedding autism expertise and capacity for publicly funded autism assessments in the new Mental Health & Wellbeing Hubs for Young People and Adults. This would align with the approach being taken in the Infant, Child and Family Mental Health and Wellbeing Hubs, and provide a much-needed universal access point to timely, affordable, and quality assessments.

# Autism-responsive schools

Autistic people want to learn:

- 3.2% of school students have an autism diagnosis<sup>9</sup>
- One third of Autistic students do not make it past Year 10<sup>10</sup>
- Very high rates of home schooling

## 3. Expand Autistic-led peer mentoring into all state secondary schools

School-based peer mentoring for Autistic students is proving to be an effective way of improving social and communications skills, building connections and a sense of belonging, improving mental well-being and enhancing self-confidence and self-acceptance.<sup>11</sup> Autistic mentoring is already being delivered in some government schools (100 by June 2023) as part of the Autism Education Strategy. Given the high rate of Autistic early school leavers, expanding mentoring programs to all 327 state secondary schools in Victoria must be a priority.



## 4. Embed mandatory training on inclusive education and autism in initial teacher training and teacher registration requirements

Autistic students (both diagnosed and undiagnosed) will likely be in every Victorian classroom. Proactively equipping our front-line workforce with autism capability as part of their teacher qualifications - rather than the current approach of teachers individually opting into autism professional development - is a critical enabler of change. It would generate significant benefits for Autistic as well as other neuro-divergent students and those experiencing learning difficulties. The Victorian Parliament's **2017 Autism Inquiry**<sup>12</sup> and the more recent **2022 Senate Autism Inquiry**<sup>13</sup> called for comprehensive approaches to teacher training. Implementation would require collaboration with the Victorian Institute of Teaching and co-design with people with lived experience.

## 5. Strengthen Victoria's Autism Education Strategy by establishing targets and measures to monitor and track progress

Victoria's Autism Education Strategy (released November 2020) aims to improve educational experiences and outcomes for Autistic school students. To track whether it's making a real difference, the Strategy needs targets for change and transparent outcome measures across key indicators to monitor impact and inform decisions about the best use of resources, including:

- Increasing Year 12 completion rates
- Increasing the rate of uptake of further and higher education
- Increasing the proportion of Autistic students sustaining their enrolment in a mainstream school
- Decreasing the rate of disciplinary absences, suspensions and exclusionary practices.

# Shift the dial on training and employment

## 6. Build the autism-responsiveness of the TAFE network including through an 'Autism Inclusion Pilot'

Autistic people are only half as likely to achieve higher level VET qualifications (Cert III and above) and University degrees as others with disability<sup>14</sup>

TAFE is the major post-school destination for Autistic people and a critical pathway to further education and jobs. The Victorian Parliament's **2021 Inquiry into TAFE and Disability Access**<sup>15</sup> highlighted widespread challenges (e.g. lack of appropriate support/adjustments and high rates of non-completion) faced by Autistic students.

Autism-responsive measures such as workforce training, support for adjustments and sensory regulation, peer mentoring and providing work-based training opportunities for Autistic students would help make a practical difference.

A TAFE Autism Inclusion Pilot that brings together some of these key measures for Autistic students from pre-enrolment to post-course transitions (inspired by the Autism Inclusion Program at the Australian Catholic University) would provide the opportunity to test and evaluate the results of targeted approaches at several TAFEs.



## 7. Invest in Autism employment initiatives, prioritising skills and labour shortage areas

- Autistic people are three times more likely to be unemployed than others with disability and eight times more likely to be unemployed than people without disability<sup>16</sup>
- One-third of Autistic people with tertiary degrees are not working<sup>17</sup>
- 86.2% of the general population agree employers should provide autism education to employees<sup>18</sup>

Autistic people overwhelmingly want to work and have skills and interests relevant to all types of jobs yet experience some of the highest rates of under-and unemployment of all disability groups. Current skills and labour shortages, the reduction in temporary visa holders, and the move towards more flexible and home-based work creates a unique opportunity to markedly lift employment rates among Autistic people. Tailored measures for jobseekers and employers will help unlock the capacity and capability of Autistic Victorians. Areas for priority focus include:

- Work readiness initiatives including enhanced career exploration for Autistic students.
- Demand-led approaches with large scale corporate and community sector employers in areas of workforce demand.
- Innovative initiatives in a range of growth sectors to strengthen the evidence base on effective employment models for Autistic people in areas beyond IT, including the creative, social, care-based, and construction sectors.
- Expansion of the successful (but very small scale) autism employment initiatives in Victoria's public sector - which will assist in meeting the public sector disability employment target of 12% by 2025.



# Improve Autistic people's health and wellbeing

## 8. Co-design a Victorian roadmap to address health and mental health of Autistic people as a companion piece to the national roadmap that is being developed

- Autistic people experience a 20–36 year life expectancy gap from the rest of the population<sup>19</sup> - many have co-occurring conditions such as Intellectual Disability, Epilepsy and ADHD
- The majority of Autistic people experience mental health conditions. Suicide risk is 7 times higher<sup>20</sup>
- Autistic children and teenagers are 10 times more likely to have a hospital admission<sup>1</sup>

Major changes are happening across every part of Victoria's mental health system following the landmark Mental Health Royal Commission. It is a critical that design and implementation of this system's transformation is autism responsive and the autism sector is working with the Department of Health to establish an Autism and Mental Health Advisory Group. A targeted roadmap to address the mental health crisis facing Victoria's Autistic community would ensure our distinct needs are not lost in the larger reform process.

Access to healthcare is a significant challenge. Repeated surveys report low autism awareness among health professionals and inaccessible/triggering health care environments. Likewise, healthcare professionals report challenges in providing care to Autistic patients and the need for further training.<sup>22</sup> High use of emergency and tertiary health services by the Autistic community reflect problems with access to preventive and primary health services.

The Disability Royal Commission found there is systemic neglect of Autistic needs in health services and called for a dedicated Roadmap, which the incoming Australian Government has committed to start developing immediately.

A complementary commitment by the Victorian Government is needed to build autism responsiveness across state-led parts of the health and mental health system such as preventive, community health and public hospitals.

While there are some promising pilot projects and innovations to build upon,<sup>23</sup> they tend to be siloed and short term so are not delivering systems level change. A comprehensive evaluation of existing approaches is needed to identify effective approaches for replication. Priority areas include autism training and resources for health professionals; autism liaison officers/navigators; tools for Autistic patients and sensory-sensitive environments.

## 9. Expand eligibility for Enhanced Maternal and Child Health Services to Autistic mothers and families with Autistic children

- Autistic mothers face high rates of prenatal (40%) and postnatal depression (60%), more challenges with breastfeeding, and are more likely to find motherhood an isolating experience<sup>24</sup>
- Autistic children are more likely to be relinquished and placed in out of home care placements than neurotypical children<sup>25</sup>

Pregnancy and postnatal health is a major risk point for Autistic mothers and mothers of Autistic children. Access to preventative, autism-responsive care would make a significant difference. Creating automatic eligibility for Autistic mothers and mothers of Autistic children to access Victoria's Enhanced Maternal and Child Health Program (EMCHP)<sup>26</sup> would enable more intensive pre- and post-natal support to assist families navigate complexities and address heightened risk factors. This needs to be accompanied by further training of maternal and child health nurses in autism (building on existing initiatives to train this workforce in early identification of autism).

# Strengthen Autistic connections, voice and advocacy

## 10. Support a strong network of peer support groups for Autistic people and their families and carers

- More than two thirds of Autistic people and parents/carers report feeling socially isolated<sup>27</sup>
- *“Without my local peer support network, I’d be lost. It’s been such a huge help to me and my family, especially during covid times.”*

Autistic people and their families are at risk of ongoing social isolation which for many has been exacerbated by the pandemic. This negatively impacts mental health and wellbeing, and hinders engagement in community life, study and work. Peer networks play a crucial role in building connections between people with shared circumstances, offering a supportive and welcoming environment, providing a source of relevant information, and strengthening capabilities as people learn from each other’s experiences and insights.

There are a range of local (place-based) and cohort-based peer support models led by different autism organisations supporting Autistic children and young people, adults and parents/carers - usually powered by community volunteers. These play a valuable role in connecting and bolstering Victoria’s Autistic community. There is a significant opportunity for the Government to partner with community organisations to extend the reach and impact of these, including for groups at higher risk of marginalisation (e.g. females, culturally and linguistically diverse, First Nations and LGBTQIA+ people).

## 11. Expand investment in Autistic advocacy, including building self-advocacy capabilities

- 45% of Autistic adults and families/carers of Autistic people do not know where to get help if experiencing discrimination (e.g. in education, accommodation, recreation and leisure)<sup>28</sup>
- More than 22% of Autistic adults report not knowing where to get help if experiencing violence, abuse or neglect<sup>29</sup>
- 77% of the general population agree that Autistic people are discriminated against

Autism-responsive advocacy support is critical to enable Autistic people and their families to access and navigate key service systems without discrimination and ensure their rights are upheld. Victorian advocacy services are currently log-jammed with high demand and many providers have closed their wait lists. Except for the organisation VALID, (who provide specialist advocacy services for adults with intellectual disability - many of whom have co-occurring autism) Victoria’s Disability Advocacy Program (VDAP) does not fund autism advocacy.

The outcomes of a lengthy review of VDAP are yet to be released or acted upon. Community surveys<sup>30</sup> and research<sup>31</sup> shows Autistic people often experience barriers in accessing generic disability advocacy services, and that such services can lack the understanding and approaches needed. The next iteration of VDAP needs to include scope for autism specific advocacy support given the sizable Autistic population, the poorer outcomes compared with other disability groups, and the need for a tailored response to address the challenges and enablers faced by Autistic people. As well as directly supporting Autistic people and their families, an autism advocacy service could also build autism competency within generic advocacy services.

*“Parents of Autistics must become very strong advocates for their child’s needs to be met at school, in community and in healthcare settings. It is a full-time job with an enormous mental load for parents to carry. I’m concerned how parents with limited resources, lower levels of education or from culturally or linguistically diverse backgrounds cope with advocating for their child. We need a dedicated service that understands our difficulty in advocating for ourselves to support us to get our needs met.”*

# A stronger Victorian Autism Plan

Victoria led the nation by developing the first comprehensive Autism Plan. However, implementation has been significantly disrupted by the pandemic. With a 'plan refresh' scheduled and the new Australian Government soon to start developing a National Autism Strategy, it is time to strengthen and evolve [Victoria's Autism Plan](#).

Key actions needed include:

- Establishing targets and indicators to measure and track changes in outcomes for Autistic Victorians across key domains – disaggregated for regions, CALD status and gender
- Legislating a requirement for Victoria to have an Autism Plan as part of upcoming amendments to the Disability Act, with periodic reporting and updating
- Including an explicit focus on Autistic people with the highest support needs (Level 3 diagnosis)
- Uplifting the Autism Plan to an Autism Strategy with rolling annual action plans.

## Endnotes

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