

## Victorian autism plan



## Our language

The government recognises the power of language in changing community attitudes and promoting inclusion of Victorians with disability.

We asked individuals and advocacy bodies about which term they thought we should use in this plan. We have chosen to use the term 'autistic people' because most people told us they preferred this wording. The term 'autism spectrum disorder' is used when referring to recommendations of the Parliamentary Inquiry into Services for People with Autism Spectrum Disorder, but is not preferred.

Throughout the plan we also use the term 'autism community' to mean autistic people, their families, carers and supporters, and autism-related organisations.

In this plan, 'Aboriginal' refers to both Aboriginal and Torres Strait Islander peoples. We acknowledge the terms 'Aboriginal', 'Indigenous' and 'Koori(e)' do not capture the entire diversity and complexity of Victoria's Aboriginal and Torres Strait Islander peoples and cultures. Our intent is always to use terms that are respectful, inclusive and accurate.

## Acknowledgment

To receive this publication in an accessible format phone 1300 880 043, using the National Relay Service 13 36 77 if required, or email the Office for Disability <ofd@dhhs.vic.gov.au>.

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Where the term 'Aboriginal' is used it refers to both Aboriginal and Torres Strait Islander people. Indigenous is retained when it is part of the title of a report, program or quotation.

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## **Minister's foreword**

The Victorian Parliament's Inquiry into Services for People with Autism Spectrum Disorder gave unprecedented insight into the daily experiences of exclusion and marginalisation faced by autistic Victorians, their families and carers.

It also demonstrated the strength and leadership of a community that is ready for change.

The Victorian autism plan sets out a vision and a plan for realising that change. It builds on core elements of Absolutely everyone: state disability plan 2017–2020, which guides Victoria's work to be more inclusive of all people with disability. It also incorporates commitments to remove specific additional barriers faced by the autistic community.

The plan will drive change in areas where autistic people have told us they are most missing out, such as community inclusion, early identification and diagnosis, and supports and pathways through key life transitions.

The plan also details actions to increase participation in education and training and to build employment opportunities in the public and private sectors. Increased inclusion relies on increased understanding. A centrepiece of this plan is a public campaign to build realistic and helpful attitudes towards autistic people. A community that is confident and informed is a community that will include autistic people in its schoolrooms, workplaces and positions of leadership.

I want to thank the many autistic Victorians, family members and carers, service providers, researchers and others who contributed to this plan. We will consolidate and expand on this engagement as we implement the plan.

By working together, we can build a community that recognises and values the achievements and contributions of every Victorian.

The Hon Luke Donnellan Minister for Housing, Disability and Ageing

## **Personal stories**

#### **Eli and Chantelle McGuinness**

Eli McGuinness is a bright ten-year-old who loves YouTube videos and wants to be a vet at the zoo when he grows up.

When Eli was three, his mum, Chantelle, noticed that he played differently from other children. He used to line up his toys and preferred to play on his own. Still, she wasn't sure if Eli was autistic because he didn't present with typical characteristics.

After Eli's diagnosis at four, Chantelle, a Gunditjmara Yorta Yorta and Wiradjuri woman who works at the Victorian Aboriginal Health Service, was determined to find out all she could about autism. She found an intensive program for autistic children to help Eli prepare for school.

'Eli came out of his shell when he started school,' she says.

Since Eli's diagnosis, Chantelle has been a strong advocate in her community, raising awareness of autism and organising events.



#### Louise Mackenzie

#### Louise Mackenzie didn't finish high school because her school principal didn't believe she was capable.

Today Louise is a doctoral candidate in architecture and film at Swinburne University, holds a full-time job as a records officer and writes for a music magazine. In 2019, Louise presented on her research at an international conference in Paris.

Diagnosed with autism in 2016, Louise says finding and keeping a job have been her biggest challenges.

'It's important that employers have an understanding of the difficulties someone with autism may face in the workplace,' she says.





#### **Bailey Müller**

Bailey Müller understands what it's like for autistic kids. The nineteen-year-old, who was diagnosed in grade five, says finding a group of friends who understood him was incredibly important.

'My friends – and they're only a small group – I know they're there for me,' he says.

Ask about what's most important to him, Bailey says, 'Having a good support network of family and friends who care – that feeling of being loved and cared for, that they're always going to be there for you.'

It's this insight and experience that has prompted Bailey to help other kids with autism.

Now studying mental health at university, Bailey wants to work with autistic children as they transition from primary to secondary school. He has also volunteered as a coach at an AFL football clinic for children with autism for the past five years.

'I just fell in love with it – I see the kids smiling and laughing and it's so rewarding.'

## Introduction

This is Victoria's plan for autistic people to enjoy opportunities for choice, participation and contribution within our community. The Victorian autism plan sets out what the Victorian Government is doing now and will do in the future to improve the lives of autistic Victorians and their families and carers. This work will be undertaken in partnership with the autism community, support organisations and service providers.

Wide consultation with the Victorian autism community has informed the plan, as well as evidence from the Parliamentary Inquiry into Services for People with Autism Spectrum Disorder. The 2017 inquiry report highlighted a range of issues that affect the quality of life of autistic people.

The inquiry, supported by extensive consultation with stakeholders, tells us that autistic people experience social isolation; lack of appropriate supports and therapy; reduced education and employment outcomes; difficulty accessing health, mental health and other public services; and exclusion from community and public events.

The findings of the inquiry and feedback from autistic people have highlighted key barriers in Victoria that contribute to these experiences:

- a lack of community understanding of autism
- limited access to appropriate assessment, diagnosis, supports and services
- additional barriers to inclusion for autistic people with intersecting identities
- barriers to accessing an education that meets the needs and aspirations of autistic students
- exclusion from employment opportunities.

Limited coordination and engagement with the autism community across government programs compounds these issues.

# About the Victorian autism plan

#### This plan aims to address key issues identified by the inquiry through a coordinated, whole-ofgovernment strategy implemented over five years.

The plan focuses on outcomes in people's daily lives. These outcomes are grouped under an outcomes framework that includes the following domains.

- Inclusive communities. This includes building positive and informed attitudes about autistic people; increasing people's opportunity to be mobile and independent; and building the capacity of mainstream workforces to serve autistic people.
- Health, housing and wellbeing. This includes increasing people's health and wellbeing through access to timely assessment and diagnosis; health and mental health services; services and supports delivered under the NDIS and through mainstream services; and suitable housing.
- Fairness and safety. This includes supporting the personal safety of autistic people; meeting the needs of autistic people in the justice and corrections systems; and meeting the needs of autistic people who face additional barriers to inclusion and accessing services.
- **Contributing lives.** This includes strengthening inclusive education for autistic students; removing barriers to employment; and actions to support the voice and leadership of autistic people.

The plan sets out actions that will contribute to these outcomes including steps the Victorian Government will take to improve NDIS outcomes. Some of these actions have already been undertaken as part of a set of early initiatives to support this plan.

The plan also outlines a process for developing an initial set of outcomes indicators and measures. These will help us measure and assess how our work is contributing to the intended outcomes.

A central commitment of the plan is a public education campaign that will inform the Victorian community about the experiences and support needs of autistic people. More informed and helpful attitudes are foundational for all other commitments in this plan.

Without timely assessment and diagnosis autistic people have little access to affordable services and supports that can in turn lead to greater opportunities and more independence. Accordingly, the plan sets out the ongoing work that we will need to do to make best practice assessment diagnosis more accessible and affordable. The plan also sets out actions to build the skills of clinical mental health services, specialist health clinics and maternal and child health nurses to undertake early identification.

Autism frequently intersects with other identities, health conditions and disabilities. The plan recognises that intersectionality can place additional barriers in the way of autistic people enjoying their daily lives. It establishes processes to allow these additional layers of diversity and complexity to be reflected in the implementation of the commitments listed here, as well as future government policy. Recent research by Amaze found that autistic people often have negative experiences of schooling and poorer educational outcomes than their peers.<sup>1</sup> For this reason, the forthcoming *Autism education strategy* will complement this plan. The strategy will describe the government's comprehensive and joined-up approach to meeting the educational needs and aspirations of autistic students in Victorian government schools, including their transition to and from school.

The plan sets out actions that will increase employment and leadership opportunities. However, it is acknowledged that long-term and large-scale change is needed to mitigate the extremely low engagement of autistic people in high-quality jobs that can become career paths.

While the plan's primary focus is responding to the recommendations of the parliamentary inquiry, there are a number of critical issues affecting autistic Victorians that are not addressed by the plan, including family violence and sexual safety. The Victorian Government is committed to reducing the risk, occurrence and impact of family violence for people with disability through its family violence reform agenda.

The final part of this document outlines how we will monitor our progress against our commitments. It describes how we will report publicly on progress against both the recommendations of the inquiry and the outcomes domains. It also sets out a process for a midway refresh of the plan, allowing us to assess which commitments need to continue, which commitments can be closed off, and where there is a need for developing additional commitments.

1 See the Amaze website <a href="https://www.amaze.org.au/creating-change/research/community-attitudes-education/">https://www.amaze.org.au/creating-change/research/community-attitudes-education/>.</a>

## About autism

Autism is a lifelong developmental disability that affects people's social communication and interaction, patterns of behaviour, interests and activities. Autistic people may also experience different reactions to what they see, hear, smell, touch or taste.

There is no definitive test for autism. Instead, professionals diagnose using developmental assessments and observation.

About one in every 100 Victorians report having autism.<sup>2</sup> However, many autistic people live without a diagnosis, and the true rate of occurrence may be higher.

Autistic people differ greatly in their characteristics, needs and their experience of disability.

Current international diagnostic standards give a limited account of the variability of intellectual development, social development, communication and behaviours. For this and other reasons, the terms 'high functioning' and 'low functioning' are not used in this plan.

On the other hand, the plan does identify a cohort of autistic people with complex needs, which can arise from a variety of circumstances, including:

- cooccurrence of additional health conditions or disability
- behaviours of concern
- interaction with the criminal justice system
- unsafe home environment
- drug and alcohol dependence.

### Attitudes towards autism

A recent Amaze survey of community attitudes to autism and a survey of autistic people and families and carers of autistic people<sup>3</sup> found that although community awareness of autism is very high, community attitudes can be barriers to autistic people's inclusion in social and economic life. In the survey of 2,424 Australian adults about attitudes to autism, more than 84 per cent of people said they thought autistic people were discriminated against and only 29 per cent thought they had a good understanding of how to support autistic people.

In Amaze's survey of 1,353 people who were autistic or were family or carers of autistic people, 20 per cent reported losing a job due to their or their family member's autism. More than half reported avoiding taking part in community life because of concerns about barriers in the environment (like crowds or levels of light or noise) or social barriers (such as needing support or worrying how people would respond to them). Fifty-two per cent reported feeling socially isolated, and 39 per cent sometimes felt unable to leave their home due to concerns about people behaving negatively towards them or their autistic family member.

In the survey, autistic people also reported positive attitudes from some people in the community, with around four out of five saying they are sometimes or often described as 'clever' (84 per cent), 'friendly' (81 per cent) or 'focused' (79 per cent).

<sup>1</sup> Australian Bureau of Statistics 2015, Survey of disability, ageing and carers 2015, TableBuilder data, ABS, Canberra

<sup>2</sup> Australian Bureau of Statistics 2016, 'Victoria', ABS, Canberra

<sup>3</sup> Jones S, Akram M, Murphy N, Myers P, Vickers N 2018, Community attitudes & behaviours towards autism; and experiences of autistic people and their families, Research report for Amaze, Carlton

# Overview of the plan's vision, principles and intended outcomes

## Vision

An inclusive Victoria where autistic people enjoy lives with real opportunities for choice, participation and contribution within our community.

## **Guiding principles**

Our guiding principles for this plan are drawn from *Absolutely everyone: state disability plan* 2017–2020:

**Autonomy:** Autonomy is about having the capacity and support to make your own decisions. It is the freedom to decide your own beliefs and relationships.

**Opportunity:** Opportunity is about having the means to control and improve your circumstances through access to education, employment and positions of leadership and influence.

**Human rights:** The Victorian *Charter of Human Rights and Responsibilities Act* protects a range of human rights, respecting the rule of law, human dignity, equality and freedom.

**Diversity:** Human rights belong to all people without discrimination, and the diversity of the people of Victoria enhances our community.

Accountability: We have developed this plan as a framework for delivering actions that contribute to intended outcomes. We expect autistic people and their communities to hold us to account over the life of this plan.

### Outcomes

The primary purpose of the *Victorian autism plan* is to drive outcomes that autistic people and their families want to see in their daily lives.

To help achieve this, we have included an outcomes framework. An outcomes framework is a tool that helps articulate:

- the change we want to see
- the actions that are most likely to produce that change
- the systems that will help us measure that change.

The outcomes framework used in this plan was introduced in *Absolutely everyone*.

Domains	Outcomes
Inclusive communities	<ul> <li>Connection – people with disability are active participants in communities aligned with their interests and identities</li> <li>Inclusion – Victoria's communities and places are welcoming and inclusive for people with disability</li> <li>Accessibility – the built and natural environment is accessible to Victorians with disability</li> <li>Mobility – people with disability are able to move around and get to the places they want to go</li> </ul>
Health, housing and wellbeing	<ul> <li>Health – people with disability achieve their optimal mental and physical health</li> <li>Housing – people with disability have housing choices that are flexible, suitable, affordable and accessible</li> <li>Wellbeing – people with disability experience a high level of wellbeing in all aspects of their lives</li> </ul>
Fairness and safety	<ul> <li>Respect – people with disability are as recognised and respected as any other citizen</li> <li>Safety – people with disability live in safety and feel secure and protected</li> <li>Opportunity – people with disability have equal opportunities to identify, pursue and achieve their aspirations</li> </ul>
Contributing lives	<ul> <li>Education and skills – people with disability actively engage and succeed in education and learning</li> <li>Employment – people with disability are engaged in flexible and sustainable employment and have opportunities to develop and succeed</li> <li>Economic independence – people with disability generate income through employment, business ownership and entrepreneurship and participate freely as consumers</li> <li>Influence – people with disability hold positions of leadership and responsibility across the private, public and community sectors</li> </ul>

Relevant departments across government will explore how data that is specific to the daily lives of autistic people could be used to show how these outcomes areas are being achieved through this plan.

Timely assessment, diagnosis and access to services and supports will be a focus of ongoing work under this plan. These things are system-level enablers that allow autistic people to experience improved outcomes and are not in themselves outcomes. For this reason, we will use other processes to monitor these system-level items.

We will also undertake ongoing work to articulate how this outcomes framework applies to the experience of autistic people with complex needs.

## **Commitments by outcome domain**

The list below summarises our commitments for making improvements in the daily lives of autistic people in Victoria. These may be refined during the process of developing the outcomes framework for this plan.<sup>4</sup>

## Domain 1: Inclusive communities

- 1.1 Increase positive community attitudes towards autistic people
- 1.2 Increase connection to culture and community for autistic Victorians
- 1.3 Increase safety and wellbeing for autistic people using public transport
- 1.4 Increase skills and knowledge across key workforces

## Domain 2: Health, housing and wellbeing

- 2.1 Improve access to autism assessment, diagnosis and early intervention
- 2.2 Increase understanding of health and wellbeing needs, including mental health needs, for autistic Victorians
- 2.3 Respond to the housing needs of autistic Victorians
- 2.4 Increase participation in sport and recreation for autistic Victorians
- 2.5 Undertake broad-ranging advocacy to get the most out of the NDIS for autistic Victorians

### Domain 3: Fairness and safety

- 3.1 Increase personal safety for autistic Victorians
- 3.2 Increase access to support services for autistic people in contact with the justice system
- 3.3 Increase the inclusion of autistic people with complex needs and their families
- 3.4 Increase the inclusion of autistic people from diverse communities
- 3.5 Increase access to culturally safe services for Aboriginal Victorians with autism

## Domain 4: Contributing lives

- 4.1 Increase the workforce capability in Victorian schools to support autistic students
- 4.2 Strengthen inclusive practices in schools
- 4.3 Improve information about education and education support systems for parents and autistic students
- 4.4 Strengthen individualised supports for autistic students
- 4.5 Increase employment of autistic Victorians
- 4.6 Increase inclusion and supports for autistic people who are parents
- 4.7 Promote the voice and leadership of autistic people

<sup>4</sup> Some actions listed in the following section have already been completed as part of early activity ahead of the release of this plan. These actions will be signalled in the first round of public annual reporting.

## **Outcomes indicators**

Absolutely everyone introduced a comprehensive set of outcomes indicators and measures for people with disabilities in Victoria.<sup>5</sup>

An adapted selection of these indicators and measures will initially be used to capture the experiences of autistic people, supported by ongoing work to identify suitable data sources. In some cases, policy areas may need to adopt a different approach to measuring outcomes.

Work has begun with the Autism Plan Advisory Group to identify the subset of indicators that best represents the outcomes that this plan is working towards. We will also work within the Victorian Government to make sure the outcomes indicators and measures are consistent with our current whole-of-government approach to measurement, which aims to promote consistent outcomes measurement across all portfolios. This will allow outcomes indicators and measures to leverage other emerging work and identify potential additional data sources. The criteria for identifying indicators will be that they are:

- meaningful to autistic people and the autism community
- likely to show change within the five-year term of the plan.

Our goal is to develop an initial set of indicators and measures after we release the plan. These will be introduced in the first round of annual reporting against this plan, as outlined in the **Implementation** section below.

A subset of indicators and measures may also be identified that are especially relevant to autistic people with complex needs.

5 See the Absolutely everyone website <a href="http://www.statedisabilityplan.vic.gov.au/">http://www.statedisabilityplan.vic.gov.au/</a>>.

## **Outcomes and commitments**

This section of the plan sets out commitments from across the Victorian Government that will address the exclusion and discrimination experienced by autistic people across many parts of daily life.

### Inclusive communities

#### **Community attitudes**

A lack of understanding and acceptance of autism in the community can make it hard for people to participate in everyday activities such as school, training, work, family, health and community services, public events and sport and recreation. In 2015 an estimated one in 12 autistic Australians had experienced discrimination in social or community situations in the previous 12 months.<sup>6</sup>

#### 'We need to be building more inclusive communities ... from the ground up.'

#### - Rural workshop participant

The government has a role to play in educating and informing the community about autism. This will support access and inclusion in the community for autistic people and their families.

Consultation survey responses highlighted the importance of changing negative attitudes and low expectations that are barriers to inclusion and can prevent autistic people achieving their full potential. 1.1. Increase positive community attitudes towards autistic people

Partner with Amaze to implement a public education campaign

The campaign will inform the Victorian community about the experiences and needs of autistic people, including those of autistic girls and women, Aboriginal people with autism and people from culturally diverse communities with autism.

The aim of the campaign is to encourage more helpful and informed attitudes, with the longer term goal of encouraging more inclusive behaviours.

Funding provided in 2017–18 has already supported the development of the public education campaign, led by Amaze.

The campaign also builds on work led by Amaze to establish baseline information about community attitudes towards autistic people. This research is compatible with broader research led by the Victorian Government to establish baseline data about community attitudes towards people with disability.

6 Australian Bureau of Statistics 2015, *Survey of disability, ageing and carers 2015*, TableTable Builder data. Situations included work, visiting family or friends, educational facilities, medical facilities, shops, restaurants, public transport and parks or recreation venues.

#### Arts and cultural life

The inquiry highlighted the need to design spaces and create activities that support autistic people and their families to take part in arts and cultural institutions and events.

Through the Creative State strategy, the government is addressing barriers to Victorians with disability taking part in arts and culture as audiences, practitioners, board members, workers and leaders.

## 1.2. Increase connection to culture and community for autistic Victorians

 Create resources, programs and activities that support autistic people and their families to take part in cultural institutions and events

An aim of this action is to increase access to options such as Relaxed Performances, highlighted in the case study below.

2. Partner with Arts Access Victoria and the autism community to increase diversity and inclusion in government-funded creative industry organisations through Creative State's Diversity and Inclusion Program *Creative State's Diversity and Inclusion* 

Program will be the main mechanism for progressing these two actions.

### Arts Centre Melbourne's inclusive performances

'We thought the play was absolutely spectacular and will indeed be back to Arts Centre Melbourne...'

> – Parent on attending a Relaxed Performance

Arts Centre Melbourne offers a program of inclusive performances that are accessible for everyone. Relaxed Performances are one of the ways the performing arts are presented for audiences who would benefit from a calmer environment, including autistic people and people with other sensory, communication or learning disabilities.

The environment is carefully adapted and embraces different audience reactions. Sound and lighting are adjusted to soften their impact, and making noise and moving around is welcome.

A designated 'quiet area' is available for anyone who needs to take a break. Pre-show resources are created to help people prepare for their visit. Front-of-house staff who have undertaken autism awareness training are available to offer assistance.

Arts Centre Melbourne works with national and international performance companies and artists, including Melbourne Theatre Company, Melbourne Symphony Orchestra, Bamboozle (UK), Circus Oz, National Theatre (UK) and Victorian Opera, to support Relaxed Performances and assist with capacity building in this sector.

Between 2015 and 2018 Arts Centre Melbourne will have staged 28 Relaxed Performances, 16 of which will take place in 2019. "My son is on the more severe end of the autism spectrum and at times can become agitated, especially during traditional theatrical experiences. Not only does the Relaxed Performance initiative mean people like my son ... are included in the arts, it means he can form a meaningful connection to creativity which transcends his disability ... We thought the play was absolutely spectacular and will indeed be back to Arts Centre Melbourne, knowing the organisation values inclusion and accessibility for those who do not fit the traditional theatre-going crowd ...'

– Parent feedback on Arts Centre Melbourne website about attending a Relaxed Performance

### **Public transport**

To take part in social, economic and cultural life, people need to be able to travel around the community. Many autistic people choose not to or are not able to operate a vehicle and rely on public transport and commercial passenger vehicles. However, autistic people often have negative experiences of using the public transport system. These negative experiences can result from intense sensory environments, changes in routine arising from repairs or emergencies, and encounters with public transport staff who have limited understanding of their preferences and behaviours.

Public transport services often make spaces available for people with disability. However, many autistic people are reluctant to use these spaces in case they are perceived as misusing a space or service intended for a person with visible disability. A key resource that can support future work to improve autistic people's experience of public transport is the new *Autism workforce capability framework* (see below). Public transport policy areas have helped to develop the framework, which will support longer term training and professional development for a range of workforces.

Public Transport Victoria is committed to improving the accessibility of the public transport network for all Victorians, including those with autism.

#### 1.3. Increase safety and wellbeing for autistic people using public transport

Improve disability inclusion by encouraging public transport operators to:

- take part in Try Before You Ride events so community members can practise using different types of accessible transport such as stationary trains, trams and buses
- prepare an accessibility action plan showing how they will make Victoria's public transport easier to use, with a focus on meeting the needs of people with invisible disability
- be accredited with the Communication Access Symbol

Victorian Public Transport operators will continue to deliver education and training to build awareness of the needs of autistic people such as:

- operator disability awareness training
- authorised officer special circumstances training
- displaying the Communication Access Symbol, which denotes training and communication
- materials for staff to assist customers with communication difficulties, including autistic people

Continue to use the Public Transport Access Committee, which advises the Minister for Public Transport and Public Transport Victoria on providing public transport that is inclusive and accessible for all Victorians, to raise the needs of autistic people

### Workforce capability

The inquiry found shortcomings in existing services for autistic people, primarily arising from workforces lacking capability to deal with their needs. Testimonials given by autistic people, carers, parents and service providers identified numerous barriers to engaging with workforces in services provided by the Victorian Government and by private providers.

Developing responsive workforces that can engage positively with autistic people is essential to the success of many commitments laid out in this plan.

A necessary first step in building the capacity of workforces is articulating the behaviours, skills and attributes that workforces need in order to serve autistic people effectively.

#### 1.4 Increase skills and knowledge across key workforces

Develop an autism workforce capability framework, outlining the understanding and skills required to meet the needs of people with autism across key workforces, including health, mental health, public transport, justice, housing, family and community services

The capability framework, which has now been finalised, will be used across government to inform capability uplift initiatives across all relevant workforces.

Workforces that are primarily in scope for this capability framework are health, allied health, mental health, community services, public transport and justice. However, the framework is intended to be broadly applicable to other workforces, including non-government workforces.

A typical capability framework describes all the capabilities required for a discrete role or function. This capability framework, however, describes only the skills, knowledge, attributes and behaviours required by the many roles for the workforces in scope for working or interacting with autistic people. Guidance about capabilities required for clinical applications such as diagnosis or specialist autism treatment and management is outside of the scope of the framework.

## Health, housing and wellbeing

## Assessment, diagnosis and early intervention

## Autistic Victorians get the diagnosis and supports they need early in life

Autistic people and their families need access to timely, high-quality diagnostic services and early intervention supports. There is broad agreement among experts that a diagnosis made early in life by qualified and experienced practitioners results in better outcomes for autistic people. However, the inquiry and consultation highlighted waiting lists for publicly funded diagnostic services, challenges in diagnosis of complex conditions, and the need for skilled multidisciplinary teams in diagnosis and intervention.

#### 'It's difficult to make up time lost in early intervention. My son could have been diagnosed 12 months earlier if my GP had the knowledge and confidence to refer us on..'

- Survey respondent

There are waiting lists to access Victorian government-funded diagnostic services, with many families currently resorting to costly private system options. There is a need to ensure equitable and timely access to diagnosis and early intervention services for autistic people, regardless of age, gender, cultural background and location. Two core areas for improvement have been identified. First, early identification and pathways to diagnosis need to be improved. Second, there needs to be increased access to timely diagnosis carried out by experienced teams of appropriately qualified professionals.

## Early identification and pathways to diagnosis

Early diagnosis gives families the information they need to access services that best support their child's development and inclusion. Often the pathways to diagnosis are not well articulated, sometimes causing additional stress and uncertainty and contributing to delays in assessment.

The consultations highlighted the work of peer support networks, advocacy groups and peak bodies to support people's journeys through the diagnostic process. By supporting the expansion of these groups, Victorians can be given greater access to information and advice on pathways to diagnosis.

Health and education workforces – including maternal and child health nurses, general practitioners, early childhood education and care professionals and teachers – play an important role in assessing whether a child, young person or adult may need further screening and referral for an autism assessment. The inquiry noted professionals often need greater capability in recognising characteristics or behaviours associated with autism. In particular, there is a need for improved understanding of girls and women, Aboriginal people and people from diverse cultural backgrounds who are autistic.

#### Better access to timely diagnosis

In all areas of Victoria, child and adolescent mental health services or child and youth mental health services provide assessments and diagnosis for autism in children. Each of these services employs an autism coordinator to support the autism-related diagnostic and referral processes. The public health system also provides autism components of assessment and diagnosis through other health services including some primary health services and hospitals.

In most cases a conclusive diagnosis for autism needs to be made by a multidisciplinary team including a paediatrician (or child and adolescent psychiatrist), a psychologist, a speech pathologist and, in some cases, an occupational therapist.

Most child and adolescent mental health services provide the recommended specialised multidisciplinary diagnosis assessment. However, workforce recruitment and retention in some professions has made providing comprehensive public assessment and diagnosis difficult in some parts of Victoria.

In October 2018, the Autism Cooperative Research Centre and the National Disability Insurance Agency (NDIA) released national guidelines for autism diagnosis. The Victorian Government will encourage uptake of the new guidelines, particularly through relevant commitments listed below.

#### 2.1. Improve access to autism assessment, diagnosis and early intervention

Establish a 2019–20 funding round to encourage innovative models of delivering assessment and diagnosis, in line with the new national guideline

Partnerships and models that blend funding streams will be encouraged. Funded projects will have a focus on better outcomes for:

- rural and regional Victorians
- intersectionality and diversity
- people with complex needs
- adults who have missed out on assessment and diagnosis.

The funding round will also be used to clarify and set in place ongoing policy arrangements within the Victorian Government relating to autism assessment and diagnosis.

Through the Child Clinical Specialist Initiative in all child and adolescent mental health services, continue to improve leadership and responsiveness in engaging, assessing and treating children aged up to 12 years old with severe challenging behaviours, including those with autism

Undertake a needs analysis to determine the training needs of maternal and child health nurses across the state in identifying children under three years of age with signs of autism and providing appropriate referrals

Develop and deliver a professional development package for maternal and child health nurses, based on the needs analysis, that will build their skills and confidence in:

- developmental surveillance for autism in children under three years of age
- providing referrals and supports for children identified as requiring assessment

Provide support and professional assistance to government-funded kindergarten teachers and early childhood educators to support the inclusion of children with additional needs, including autism

Develop an inclusive early education web portal that gives parents and early childhood educators a single source of information about inclusion for young people with developmental delays, including autism

Explore ways to improve access to multidisciplinary assessment and diagnosis in rural and regional areas such as through technology, training opportunities, mentoring and flexible service delivery models

Build the capability of child and adolescent mental health services to assess and diagnose autism in accordance with the new national guidelines

#### Health and wellbeing

A recent study from New South Wales found that autistic people have elevated mortality across the lifespan. The overall comparative mortality rate is about twice that of the general population.<sup>7</sup>

Poor mental health is more common in autistic people than in the general population and is associated with long-term negative outcomes.<sup>8</sup>

Autistic people may face barriers accessing health and mental health services due to environments interacting with sensory sensitivities and communication styles. Additionally, autistic people attending services to address a specific health need may find that clinicians' attention is unhelpfully diverted away from their presenting needs and towards managing their autism.

There is a need for stronger collaboration between services and greater understanding of autism among health (including mental health and allied health) professionals. There is also a significant need for work to ensure that autistic people's encounters with health services do not direct them to unsuitable care options and do not use health resources and programs to address other underlying issues such as behaviours of concern.

Stakeholders said it is important that health and allied health service providers receive autism training. The consultations for this plan identified examples of good practice among health professionals across Victoria to build services that welcome and include autistic people. Several commitments below aim to encourage and replicate good practice of this kind.

Building understanding about autism among health professionals is essential for health services to be welcoming, accessible and easy to navigate. The consultations also highlighted the need for strong leadership and collaboration, and for better connections between health professionals and autism organisations and advocates.

The Victorian Government has a role in supporting the professional development of hospital, community and other health workforces. This will help to build more responsive and inclusive services that better meet the diverse needs of autistic people and their families.

<sup>7</sup> Hwang YI, Srasuebkul P, Foley KR, Arnold S, Trollor JN 2019, 'Mortality and cause of death of Australians on the autism spectrum', *Autism Research*, vol. 12, pp. 806–815

<sup>8</sup> Brugha TS, McManus S, Bankart J, et al. 2011, 'Epidemiology of autism spectrum disorders in adults in the community in England', Archives of General Psychiatry, no. 68, pp. 459–866

## Peninsula Health emergency department



6

'I'm enjoying that I can apply my personal experience and my knowledge to fill this need bit by bit and improve the care we provide.'

> Antje Walter, parent of two autistic children

Antje Walter knows firsthand how stressful a trip to the emergency department (ED) can be for an autistic person. Two of her children are autistic; she is also a nurse in Frankston Hospital's ED.

'I can understand what it's like from a health professional's point of view trying to assess, treat and examine these patients, but I also know what it's like as a mum, as a carer,' explains Antje.

In 2016, as part of her Graduate Diploma in Advanced Emergency Nursing, Antje wrote a paper on how EDs can improve the care they provide for patients with autism. It has led to Antje being appointed to introduce some of the ideas, along with other suggestions from patients, at Peninsula Health. 'We've developed a passport for individuals with autism which either the individual themselves or their carer can fill out when they come into the ED,' says Antje.

Patients or their carers can use the passport to identify their particular needs. For example, are they sensitive to noise, lights, touch or pain? What triggers behavioural challenges? Are they verbal? The passport can also become part of the patient's electronic health record, making it easily accessible every time they present to a hospital.

Antje has also developed some communication materials based on a communication system used in all special development schools.

'On one board, they can point to things they may need. If something hurts, they can point to exactly where it hurts, without having to tell us verbally.' Another board is used to show what will happen during an assessment, such as looking into a patient's ears or checking their temperature.

'By using pictures the patient can be prepared, and it makes them a lot more cooperative with the assessment. It also makes it a lot less stressful for them when they're already feeling unwell and have had their routine completely upset.'

The passport and communication boards are now in use at Frankston ED. Antje has also been running education sessions with staff who plan to use the materials.

She has also recently put together boxes with visual, tactile and auditory sensory equipment, such as noisecancelling headphones, to reduce sensory overload. These are in the paediatric area and can be used to help calm paediatric and adult patients affected by stress and anxiety.



## 2.2. Increase understanding of health and wellbeing needs, including mental health needs, for autistic Victorians

Support a Royal Children's Hospital pilot to reduce avoidable presentations and length of stay for autistic children in its paediatric emergency department

This project aims to decrease crisis presentations to EDs, reduce the number and duration of admissions to hospital, and radically improve the care for Victorian autistic children and adolescents, as well as children and adolescents with intellectual disabilities and behaviours of concern.

As part of implementing *Victoria's 10-year mental health plan*, continue to strengthen the public specialist mental health system to ensure children aged up to 12 years old and their families have access to the support they need when they need it

Consider approaches to strengthen the capability of clinical adult mental health services to recognise, assess and respond appropriately to autistic adults

Test workforce models that can be expanded across Victoria to improve the health and mental health of autistic people through the Advancing Practice in Allied Health Workforce Funding Program

Support the delivery of health workforce information sessions about autism in women and girls

Identify needs for accredited autism training to improve services for autistic people

In consultation with peak bodies, identify available information and resources on autism as well as further information that needs to be developed

Build autism competency across workforces through Department of Health and Human Services policies and guidelines to skill health and mental health workforces to respond positively to autistic Victorians

Explore training opportunities for rural and regional areas through greater use of technology, such as telehealth, mentoring and peer support/secondary consultation models

#### Housing

Housing provides a foundation for all Victorians to lead independent and healthy lives. There continue to be barriers for autistic people in accessing affordable, safe and sustainable housing. The inquiry highlighted the current shortage of quality housing for people with disability, including autistic people, and the varying levels of housing support autistic people require, depending on their level of need and presence of co-occurring conditions.

Consultations also highlighted that we need to understand better the breadth and depth of the housing challenges for autistic people to drive greater oversight and accountability.

There are opportunities to consider existing housing options and supports for people with specific housing needs, and links with the NDIS such as short-term accommodation.

Innovative approaches will help autistic people access appropriate and affordable housing. This will contribute to long-term benefits for autistic people including improved social inclusion, independence and economic participation.

## 2.3 Respond to the housing needs of autistic Victorians

Continue the Victorian Housing Register, which started in September 2016 and brings together public and community housing waiting lists into a single place

The register provides more equitable access to public and community housing, including for autistic Victorians, with places on the register determined by eligibility and current situation, creating a fairer system for all.

Together with key stakeholders, identify the needs of autistic people who are accessing public housing to guide specifications for new and upgraded housing

Consider options to promote the use of the Housing Options Finder, which helps Victorians understand their rights and pathways to access social housing

Strengthen information in the Housing Options Finder about how various circumstances, including autism, are considered through the Victorian Housing Register

Through Absolutely everyone, increase the accessibility and affordability of housing for all people with disability, including those with autism, through initiatives such as private rental brokerage, increasing the supply of community housing and better meeting accessibility and adaptability needs in new public housing construction

Through Homes for Victorians, implement the Social Housing Growth Fund to fund projects to deliver more social housing that will be adaptable and flexible and able to support eligible clients with special needs

The fund's key aim is to underpin new approaches to deliver social housing. Over the next five years the fund will support up to 2,200 new social housing places.

#### **Sport and recreation**

Sport and recreation are vital to Victoria's social and economic life. Participation in sport and recreation is important for health and wellbeing and can contribute indirectly to engagement in other areas including education, training and employment. The inquiry highlighted the need to increase activities and programs so more autistic people can take part in sport and recreation.

The government is working with partners in the sport and recreation sector to create more opportunities for people with disability, including autistic people, to take part.

#### 2.4 Increase participation in sport and recreation for autistic Victorians

Develop programs and partner with community organisations to make public parks more accessible and inclusive for autistic people

Develop a new specialist autism inclusion program in consultation with sports organisations and the autism community to provide more sport and recreation opportunities across Victoria for autistic people

Host an inclusion forum and establish an ongoing network of sporting organisations, local governments and the autism community to build awareness of the needs of autistic people and build the capacity of sporting clubs and local governments to meet these needs

Expand the successful AFL Auskick program for children with autism to other sports such as Special Olympics, swimming, netball, hockey, tennis, tenpin bowling, golf, gymnastics, outdoor recreation and horse riding through the Access for All Abilities program

In consultation with the AFL, provide a new sensory room using the principles of universal design as part of the redevelopment of Marvel Stadium

Expand the reach of Access for All Abilities Play (a free information and referral service) from a metropolitan service to a statewide service to assist people with disability across Victoria to become involved in sport and recreation

Promote local governments' adaption of recreation sites and programs so they meet a diverse range of needs, including the needs of autistic people

## Museums Victoria's Autism Friendly Museum



Museums Victoria welcomes just under two million visitors each year to Melbourne Museum, Scienceworks and the Immigration Museum. Visitors represent a wide range of community members, including autistic children and adults.

Since 2014 Museums Victoria has worked with partners Amaze and the Department of Education and Training to serve autistic people visiting their museums.

Museums Victoria's Autism Friendly Museum initiative welcomes autistic people and their families and schools by providing better information, a sense of welcome and resources to support independent access and participation. Actions include:

- raising autism awareness among front-of-house staff and supporting staff to be confident in welcoming and engaging autistic visitors
- including online resources in the form of social stories that show children what they may see and experience during a visit to the museum
- maps of low- and highsensory spaces at the Immigration Museum, Melbourne Museum and Scienceworks
- communicating internally and externally about the project and the web resources to ensure awareness and community use
- continuing to evaluate and update the social stories and maps with autism audiences and stakeholders.

Since being published in mid-2016, more than 30,000 visitors have viewed the Autism Friendly Museum homepages, and more than 4,000 have accessed the social stories.

Museums Victoria is now producing resources for very young visitors, including the social story for the Pauline Gandel Children's Gallery at Melbourne Museum. Social stories for the new Ground Up exhibition at Scienceworks and for outreach visits to kindergartens are also available.

Families with autistic children have provided an important contribution to developing the social stories and the sensory maps to make sure they are useful.

## Parks Victoria's autism-friendly visits



Parks Victoria is increasing the accessibility of its parks for autistic people by providing 'social scripts'.

Developed in collaboration with Amaze, the social scripts have photographs and simple text to show children what they may see and experience during a visit to a park. Parents can use this information to create a story that best suits their child and their planned park visit. The social scripts are available on the Autism Friendly Parks webpage.<sup>9</sup> There are a variety of park experiences for autistic people to participate in.

The social scripts are also available in Key Word Sign Australia format to support children who are learning to use Key Word Sign to communicate. In 2018 Parks Victoria won a national tourism award for this initiative under the Specialised Tourism Services category.

<sup>9</sup> For more information, visit the ParksVictoria website <a href="https://parkweb.vic.gov.au/visit/improving-park-access-for-all/autism-friendly-visits">https://parkweb.vic.gov.au/visit/improving-park-access-for-all/autism-friendly-visits</a>.

#### National Disability Insurance Scheme

The NDIS represents a significant opportunity to transform the lives of Victorians with disability and their families and carers.

The inquiry identified two key areas in which the NDIA can better support autistic people and their families: first, by providing clear and timely information about the NDIS to potential participants and participants; and second, by ensuring NDIS planners have the skills and knowledge to engage with autistic participants.

The Victorian Government is committed to maximising the benefits of the NDIS for autistic people in Victoria, including people in rural and regional areas, Aboriginal Victorians, Victorians from culturally diverse backgrounds and LGBTI+ Victorians. The government will undertake a range of actions to ensure autistic people successfully transition to the NDIS, including advocacy, monitoring and supports. These actions will be informed by the recommendations of the inquiry and ongoing consultation with autistic people, their families and the sector.

The Victorian Government understands that the quality of services and safety of autistic people are paramount. The powers of the Disability Services Commissioner have been strengthened to support a 'zero tolerance' approach to abuse of people with disability, including autistic people. The sector has also been consulted about introducing a registration and accreditation scheme for disability workers in Victoria. 2.5 Undertake broad-ranging advocacy to get the most out of the NDIS for autistic Victorians

2.5.1 Use Victoria's role on the Disability Reform Council to advocate for the needs of autistic Victorians in the NDIS

Engage with the Commonwealth and other states and territories to ensure that no autistic person loses existing protections due to transferring to the NDIS

The government will retain responsibility for quality and safeguards for autistic people who are not NDIS participants.

Advocate for improved outcomes for NDIS participants, including timely access arrangements and appropriate levels of behavioural support

Continue to advocate for the diverse needs of autistic people and their families to the NDIA through advocacy as a member of the Disability Reform Council, including communicating the findings of the inquiry and this plan to the council and the Commonwealth Minister for Social Services

Advocate for services currently available under the Commonwealth's Helping Children with Autism program, or their equivalent, to be available under the NDIS

Advocate for innovative housing models under the NDIS that can meet the needs of autistic people

#### 2.5.2 Support service providers and autistic Victorians to transition to the NDIS

Strongly advocate for improved access and planning outcomes for autistic NDIS participants, with a focus on the experience of participants with complex needs

Implement the Transition Support Package to help Victorians with disability, their families and carers, the disability workforce and service providers to transition to the NDIS

Continue to provide early childhood intervention services that ensure children receive appropriate therapy and supports during their transition to the NDIS

Children who are ineligible for the NDIS based on residency grounds and who meet the program requirements will continue to receive early intervention services.

Continue to advocate for NDIA-registered service providers of early childhood intervention to deliver evidence-based practices

Invest in workforce development, training and skills to build a world-class disability workforce in Victoria through the government's *Keeping our sector strong: Victoria's workforce plan for the NDIS* 

Keeping our sector strong provides funding to identify and implement best practice approaches to supporting people with high and complex needs and behaviours of concern.

Build the readiness of community autism organisations for the NDIS

Engage the Aboriginal community to deliver Aboriginal cultural safety and competency training to autism-specific service providers

Establish place-based Aboriginal disability coordination and planning networks in each division of the Department of Health and Human Services to help the Aboriginal community to engage with the NDIS

## 2.5.3 Monitor the experiences and outcomes of autistic people transferring to the NDIS

Work with the NDIA to monitor the experiences of and outcomes for autistic people and their families in accessing the disability supports and respite they needs

Closely monitor the NDIS' Early Childhood Early Intervention scheme to ensure services are adequately provided across Victoria, particularly in rural and regional areas

### Fairness and safety

#### **Personal safety**

Some autistic people, particularly younger people, don't pick up on signs that a situation or environment may not be safe. This is often associated with their processing of sensory information and their understanding of social cues.

Autistic people can sometimes need assistance in unfamiliar environments or when encountering stressful situations. Younger autistic people can also wander or elope for a number of reasons. Wandering and elopement can put autistic people into unsafe situations and is a significant cause of concern for family and friends.

## 3.1 Increase personal safety for autistic Victorians

Develop a fact sheet for all police employees about autistic people and potential contacts with police, including how to respond to people who are wandering

Build the capability of police in personcentred approaches for people with disability, including autistic people

Through the Homes for Victorians initiative and Victoria's homelessness and rough sleeping action plan, invest in homelessness services to intervene earlier to prevent homelessness, provide stable accommodation as quickly as possible, provide support to maintain stable accommodation and build effective and responsive homelessness services

This will strengthen services to vulnerable people, including those with autism, by:

- extending homelessness assessment and planning capacity across Victoria's prison system to prevent homelessness and intervene early
- placing Enhanced Housing Pathways workers in the three social housing and homelessness launch sites to test a more intensive approach to supporting people exiting prison into private rental or social housing.

#### Justice

Autistic people are more likely to be victims and witnesses of crime than offenders; however, when they come into contact with the justice system, they face significant challenges. There is a need to recognise the additional disadvantage of vulnerable autistic people in the justice system.

The inquiry and consultations highlighted the need for the corrections system to develop a clearer picture of the number of autistic people in custody in Victoria and to consider opportunities to support them better. We need to improve the training and development of our justice workforce, including Victoria Police, courts and corrections staff, and to connect autistic people early with appropriate supports to avoid repeat contact. A focus on supporting autistic people in contact with the justice system will help improve transition and reintegration into the community.

Because the first contact with the justice system is often with police, survey participants indicated that developing the ability of police to interact effectively with autistic people is a priority.

## 3.2 Increase access to support services for autistic people in contact with the justice system

Support the continued ability of the Children's Court Clinic to undertake comprehensive assessments that may identify autistic children and parents and lead to referral to appropriate support services by child protection or youth justice

Develop a Youth Justice Strategy to strengthen access, referrals and engagement with education and training, employment, housing and health and wellbeing support for young people in youth justice, including a focus on those with disability and young autistic people

Work to maximise the opportunities offered by the NDIS to ensure continuity of services and supports for offenders in corrections and young people in youth justice

#### Ensure that:

- initial assessment and planning workers in prison are able to provide appropriate housing information and advice for vulnerable people, including those with autism, transitioning from prison to release in the community
- prisoners are informed about housing and homelessness services, including through post-release supports

Build the capability of youth justice workers and corrections staff in approaches for people with disability, including autistic people

Establish a Victorian Civil and Administrative Tribunal disability reference group to help develop reforms to service delivery

#### **Complex needs**

Autistic people with complex needs and their families can face additional barriers to participating in the community and the economy. They can also require more intensive levels of support but are often shut out by services that are reluctant to take them on. Many parents of autistic people with complex needs act as primary carers well past the age of retirement and express concerns about succession planning for when they are no longer able to provide this care.

Some but not all autistic people with complex needs can exhibit behaviours of concern, adding additional layers of need and sometimes placing the person in contact with police and corrections.

Feedback through work on this plan has indicated that people with complex needs and their families don't always benefit from actions that address the needs of autistic people more generally. For this reason, this plan establishes processes for bringing expertise on complex needs into any relevant policy work.

An area of focus will be Victorian advocacy around how the NDIS can best service people with complex needs (see NDIS section above).

A complementary focus of Victorian Government action will be to build the capacity of mainstream services to respond appropriately to autistic people with complex needs.

## 3.3 Increase the inclusion of autistic people with complex needs and their families

Fund organisations that have a focus on the needs of adult autistic people to increase the sustainability and reach of their work

Establish twice-yearly 'complex needs' forums to provide advice to the Victorian Government that will allow current and future policy to take in the circumstances and needs of autistic people with complex needs

#### LGBTI+ people

Autistic people are more likely to be trans or gender diverse than the general population. They often become aware of their sex and gender identity at a young age but may not make this known to others to avoid additional layers of exclusion, discrimination and abuse.

Both autistic people and LGBTI+ people have poorer health and mental health outcomes compared with the general population and experience greater social disadvantage. LGBTI+ autistic people should be able to draw on safe and appropriate services to meet their health, wellbeing and education needs.

#### Girls and women

Diagnosis rates of autism in girls and women are not indicative of the rate of incidence. This is most likely strongly influenced by poor public and professional understanding of how autism presents differently.

Girls with autism are generally identified and diagnosed later in life, often missing opportunities for early interventions. Girls who have been able to adapt their behaviour to mimic peer behaviours are sometimes first identified in the transition from primary to high school.

There is a need to improve understanding about the presentation of autism in girls and women to ensure they have access to appropriate supports and services.

#### **Culturally diverse communities**

The inquiry highlighted additional barriers to assessment, diagnosis and support in culturally diverse communities. Some of these additional barriers arise from the limited capacity of services to provide appropriate offerings to culturally diverse communities. Other barriers arise from the specific cultural expectations and beliefs of communities in which autism may be poorly understood and a source of stigma.

#### **Rural and regional Victoria**

The barriers faced by autistic people and their families are heightened in rural and regional locations. Autistic people often have to travel many hours to access the services and supports they need. There is a need to train, recruit and retain service providers in rural and regional communities.

## 3.4 Increase the inclusion of autistic people from diverse communities

Support autism organisations that address the needs of key cohorts, including the LGBTI+ community and girls and women

Partner with community organisations to provide advocacy and support for culturally diverse communities

Establish twice-yearly autism diversity forums to provide advice to the Victorian Government that will allow current and future policy to address autism intersectionality

#### **Aboriginal people**

Little is currently known about the true rate of incidence of autism in the Victorian Aboriginal population. Barriers to accessing assessment, diagnosis, services and supports are compounded by a lack of culturally safe service options.

Self-determination is necessary for better identification and support of autistic Aboriginal people. Aboriginal families should be able to make decisions in partnership with skilled workforces drawn from their own communities.

## 3.5 Increase access to culturally safe services for Aboriginal Victorians with autism

Explore improved training for health and human service providers that deliver supports for Aboriginal people with autism

Support cultural safety in health and human services organisations that provide services to Aboriginal autistic people

Explore options to support rural and regional Aboriginal students studying psychology, speech pathology and social work through the Aboriginal Nursing, Midwifery and Allied Health Cadetship and Graduate Program

## **Contributing lives**

#### Education

In 2015 an estimated 22,600 autistic children and young people living in Victoria attended school.<sup>7</sup> The Victorian Government is committed to establishing Victoria as the Education State, in which every Victorian has equal access to the knowledge and skills to shape their lives. Part of this work is to promote inclusive practices in schools so they can better support all children and young people.

The inquiry and consultations heard about some of the challenges facing autistic children and young people in accessing school education.

Consultation survey responses highlighted the importance of coordinating supports and strengthening inclusion in schools by:

- building the capabilities of school leaders to create an inclusive school environment
- emphasising the benefits of inclusion for all students and staff
- strengthening accountability for implementing inclusive practices and for supports provided.

In response to the inquiry recommendations, the Department of Education and Training took a number of immediate actions, including:

- providing 60 scholarships for teachers to undertake the Master of Education (Applied Behaviour Analysis) through Monash University
- doubling the number of scholarships offered to Victorian government school teachers to complete the Graduate Diploma of Teaching Students with ASD through the Autism Teaching Institute to 40 in 2018
- appointing eight **regional autism and inclusion consultants** (two in each of the four regions of the state) to provide evidence-based information, training and mentoring to school leaders and other school staff in Victorian

government schools on best practice in supporting autistic students

- working with Yellow Ladybugs to produce *Spotlight on girls with autism*, a resource for teachers to better understand and support autistic girls
- working with the Victorian Equal Opportunity and Human Rights Commission to design autism training that can be delivered across the government, Catholic and Independent school sectors
- undertaking the **Project to Accommodate Students with a Disability in Schools** to establish a prioritised and evidence-based specialist infrastructure pipeline, covering both inclusive and/or standalone specialist school sites.

In 2017 and 2018, the Department of Education and Training and Amaze worked with stakeholders to develop priorities for better supporting autistic students in Victorian government schools. These are outlined below.

The Department of Education and Training will build on these priorities to develop an evidencebased strategy that will describe the department's comprehensive and joined-up approach to meeting the educational needs and aspirations of autistic students in Victorian government schools.

#### School staff capability

Improving knowledge of autism and building staff capability in supporting autistic students applies to school staff at all levels – including school leaders, teachers and education support staff.

#### 4.1 Increase the workforce capability in Victorian schools to support autistic students

From 2019, provide additional scholarships (75 over four years) to continue to support teachers and regional allied health professional to undertake the Master of Education (Applied Behaviour Analysis)

An additional university course has also been included in this initiative to deliver a Master of Education (Autism Spectrum Disorder) through Australian Catholic University.

Provide more scholarships to Victorian government school teachers to build their capabilities to teach autistic students

Work in partnership with teacher training institutions to strengthen teacher capability in teaching autistic students

Improve the professional competency of Victorian government school teachers to teach students with disability, including autism, through scholarships to undertake a Master of Education (Inclusive Education)

Roll out school-wide positive behaviour support that assists school professionals to improve social behaviour and learning in schools

Work with Yellow Ladybugs to produce *Spotlight on girls with autism,* a resource and website for teachers to understand and support autistic girls

Build all new Victorian government schools, including mainstream schools, tech schools and specialist schools, with flexible learning spaces that are appropriate for teacher training and professional development

Existing schools that undergo significant upgrades will also have these design features included.

Improve online resources and training for early childhood professionals to increase knowledge and confidence in supporting young children with disability and developmental delay to meet their learning and developmental needs

Investigate how to build and maintain relevant allied health expertise in the education system in rural and regional areas

Identify how best to ensure that all staff in Victorian government schools are aware of their legal obligations relating to autistic students, including obligations around enrolment and making reasonable adjustments for autistic students

#### Inclusive school environment and family-school partnerships

Schools are responsible for providing an inclusive social environment to support all students, including those with autism, and addressing any negative attitudes and behaviours towards students with additional needs to ensure an inclusive education experience for all. Strong family and school partnerships are vital for positive school experiences and engagement for autistic students and the wider school community. Families play an important role in children having positive experiences of school, and clear communication between schools and families can improve social, wellbeing and educational outcomes for autistic students.

Under the \$40 million Inclusive Schools Fund, Victorian government schools have been provided with quality new spaces and more inclusive facilities, based on best practice research and design. Since 2015, this fund has supported 181 projects which build and enhance a school culture of inclusion as well as enhancing the participation of students with disability, including those with autism.

#### 4.2. Strengthen inclusive practices in schools

Continue to provide opportunities for families who homeschool their children to seek a partial enrolment at their local government school so their children can access particular subjects or activities at school

Support the expansion of the I CAN Schools program, which provides face-to-face mentoring for autistic students by autistic mentors in Victorian government schools

Support the I CAN Network to develop, pilot and evaluate an online mentoring program for autistic children and young people to develop self-acceptance, belonging, optimism and confidence at school

Expand the Bully Stoppers online toolkit to include evidence-based anti-bullying practice guides and resources for schools, with a focus on students with disabilities, including those with autism

Scope models of outreach success, including for regional and rural Victoria, to determine evidence-based best practice

Support Victorian government schools to review and refine their inclusion policies and provide high-level information about the policies on school websites

This will help families to see how each school is promoting inclusive education.

Develop policies and practices to provide inclusive practices in the new inclusion hub schools

Investigate options to collect information about a student's autism diagnosis to support schools to comply with the Disability Standards for Education for enrolment of autistic students in Victorian government schools

# I CAN Network in schools



### 6

'I like how I get to meet and talk to other people who are also on the spectrum ... I CAN is really fun and helps me overcome negative thoughts and keeps me more positive.'

- I CAN student participant

Coburg High School was one of three Victorian government schools to trial the I CAN schools pilot program in 2016. It started the program with six students in fortnightly sessions with an autistic mentor, with the aim of building confidence and understanding emotional intelligence. In 2017 Coburg High School students took part in stage 2 of the program, which focused on developing leadership skills, emotional intelligence and training to become a mentor.

One student had challenges with communication and experienced low self-esteem. After taking part in stage 1 of I CAN he had built his confidence to the point that he was invited to be master of ceremonies at the I CAN school presentation night. Another student experienced significant anxiety and was becoming increasingly disengaged from school. I CAN mentoring helped him explore these issues and work on problem solving with likeminded peers and experienced mentors. At the end of the program, he provided an engaging and entertaining presentation on his favourite topic and great strength - soccer.

The school's I CAN coordinator, David Snaddon, says the program has 'contributed to a culture of understanding, empathy and enhanced capacity in staff'. The school has been impressed with the growth and development it has seen in students involved in I CAN. It sees the program as a longterm investment in a positive school culture and hopes the students being mentored today will become the mentors of tomorrow.

# 4.3 Improve information about education and education support systems for parents and autistic students

Review and expand the existing online resources to guide parents when choosing schools for their children with disability

Use the Victorian Home Education Advisory Committee as issues arise to clarify:

- the existing supports available to parents who homeschool their autistic children, including online resources and partial enrolment options
- the expectation that parents considering homeschooling for their autistic children contact their school to discuss options for better engagement in the school setting

# Targeted and individualised supports and student wellbeing and mental health

Promoting positive student wellbeing and mental health for autistic students is important to help them to feel less stressed and anxious, more positive about their abilities and future opportunities in education and employment, and more socially included.

### 'Fairness isn't about everybody getting the same; it's about everybody getting what they need.'

#### - Education workshop participant

We need to strengthen the system of supports currently available to schools to identify and respond to the learning and support needs of more students with disability, including autism.

#### 4.4 Strengthen individualised supports for autistic students

Pilot and refine tools and processes to inform research into a new school funding and support model for Victorian government schools to better meet the needs of students with disability, including autism

Promote the *Responding to requests for NDIS funded therapy in schools* guidelines, which were developed to assist school principals with requests for NDIS-funded therapy to be delivered in Victorian government schools

Improve career education and pathway planning for students with disability by developing resources and delivering professional development for teachers, career practitioners, students, parents and employers

Invest in student health and wellbeing, including by:

- employing more allied health service staff, such as speech pathologists and psychologists, in the education system
- funding mental health practitioners in every Victorian government secondary school campus by 2022

Examine relevant areas of vocational education and training policy and programs in Victoria to ensure:

- the specific issues autistic Victorians face are appropriately addressed in professional development delivered to VET practitioners through such entities as the VET Development Centre
- government-funded support programs offered by Learn Locals and TAFEs, such as Reconnect, are able to respond to these issues through targeted and appropriate supports
- high-quality training and support is available across the state for more people with disability and their carers to access skills, training and jobs
- the Victorian training system is able to meet demand for high-quality training for an expanding NDIS workforce

### Employment

Increased participation in the workforce would benefit many autistic people and would strengthen the Victorian economy. However, autistic people are under-represented in the workforce – Australia-wide in 2015 an estimated 50 per cent of working-age autistic people were not in the labour force. Of those who were, half were employed part time.<sup>10</sup>

The inquiry and consultations highlighted a range of challenges that autistic people face in both gaining and sustaining employment. The challenges include:

- a lack of understanding among employers of the needs of autistic people
- the need for more support to negotiate the social and communication demands of traditional workplaces (such as interviews)
- difficulties in establishing flexible workplace arrangements and negotiating reasonable adjustments.

The government is a large employer and has an important role to play in creating and supporting sustainable employment opportunities for autistic people.

Survey participants highlighted the importance of a commitment from the Victorian Government to employ autistic people.

<sup>10</sup> Australian Bureau of Statistics 2015, Survey of disability, ageing and carers 2015, TableBuilder data. This estimate includes autistic adults aged 18–64

#### 4.5 Increase employment of autistic Victorians

Enhance employment of autistic people in both the Victorian public sector and broader Victorian economy by implementing actions in *Every opportunity: Victorian economic participation plan for people with disability 2017-2020* 

Actions under Every opportunity include:

- increasing investment to provide more targeted opportunities for people with disability, including by establishing a dedicated disability employment support stream within the Jobs Victoria Innovation Fund and piloting a new employer liaison role to secure more jobs for people with disability
- using the STEM and Agri Lab models to create employment opportunities for young rural autistic Victorians
- creating 50 paid internships for people with disability, including autistic people, across the Victorian economy
- using the Small Business Festival Victoria 2018 to raise awareness about inclusion and to showcase the contribution that people with disability, including autistic people, make as small business owners and employees
- evaluating the RISE employment initiative for autistic people at the Department of Health and Human Services and considering rolling it out across other Victorian public sector bodies
- promoting the whole-of-government social procurement framework to enhance employment opportunities for autistic people.

Through the Jobs Victoria Innovation Fund, implement the Dandelion Program to place 20 young autistic jobseekers into small- to medium-sized enterprises in Victoria

Develop and implement a Victorian public sector disability employment action plan focused on making attraction, recruitment, retention and career progression strategies inclusive of all people with disability, including autistic people

This will be undertaken in partnership with the Victorian Public Service Employees with Disability Network (the Enablers).

### Case study

## RISE at the Department of Health and Human Services



The Department of Health and Human Services introduced the RISE program in 2017 to provide employment opportunities for autistic people. Developed with the support of Specialisterne Australia, RISE is enabling autistic people to be valued for their unique skills and is helping to build a departmental workforce that better reflects the community it serves.

Adam Walton is employed through the RISE program. Before joining RISE, Adam worked intermittently in workplaces that didn't accommodate him and didn't enable him to develop a career path. 'I wasn't always so fortunate. I finally had a good run of luck after a decade or more of career dead-ends, fruitless job interviews, unsympathetic and ill-informed workplaces, and frustration.'

Adam sees taking part in the RISE program as a major step in building a career. 'I have been lucky, and I have a lot to thank my lucky stars for. But I am aware that many people like myself have not been so blessed with good fortune ... I hope the program I participated in sets a precedent. I hope it is the first of many such initiatives in this country.'

Adam is passionate about reshaping the way companies consider and hire applicants. The RISE program gives Adam an opportunity not only to shape a career path but to be an advocate and example for other autistic people.

### Parents with autism

Parents' capacity and wellbeing has a profound impact on the health and wellbeing of children and young people. Autistic parents often have little formal support that assists them in raising their children, who may also be autistic.

Autistic parents should be able to raise their children with the confidence that any services and supports they draw on will meet their needs while recognising their agency and expertise.

The inquiry noted there is little formal research into the experiences and needs of autistic parents and their families and a lack of targeted services to support autistic parents.

The Victorian Government acknowledges and promotes Amaze's Parenting skills guide for autistic parents.<sup>11</sup>

# 4.6 Increase inclusion and supports for autistic people who are parents

Together with stakeholders, identify the resource needs of autistic parents, scope existing resources (such as the *Parenting skills guide for autistic parents*) and make recommendations for additions or enhancements

Include a focus on support for parents and carers in twice-yearly issues-based forums involving the autism community, crossgovernment representatives and stakeholders

Work with autism stakeholders to develop and implement peer support models that respond to the needs of autistic parents

### Voice and leadership

The inquiry and consultations highlighted that autistic people want to be involved and should be involved in developing policies and programs that affect them.

The government recognises that autistic people are experts in what is best for them and commits to involving autistic people, their families and supporters when developing policies. The Victorian Government looks to local governments, service providers, professionals and the community to support this commitment to inclusion.

The government established the Victorian Autism Plan Advisory Group to advise on developing this plan. Members represented a broad range of autistic people, their families and supporters. The government also engaged with the broader autism community through targeted meetings, workshops and an online survey.

11 See the Amaze website < https://www.amaze.org.au/2017/05/amaze-launches-ground-breaking-resource-for-autistic-parents/>.



#### 4.7 Promote the voice and leadership of autistic people

#### 4.7.1 Involve autistic Victorians and their families in improving services and supports

Establish and operate an Autism Plan Implementation Advisory Group to advise government on implementing this plan

Partner with the autism community to introduce twice-yearly issues-based forums involving cross-government representatives and stakeholders to ensure that autistic people, their families and supporters are engaged and heard

Forums will include a focus on improving service integration and coordination, support for life transitions, support for parents and carers, emerging research and NDIS transition.

Engage with the new Autism Success Network within the Victorian Public Service Employees with Disability Network when developing and implementing disability action plans and other internal policies and processes

# 4.7.2 Work with autism organisations and others to ensure a sustainable and vibrant network of community support led by and for autistic Victorians and their families

Strengthen autism support organisations and community groups to:

- promote community understanding and acceptance of autism
- better connect autistic people and their families
- provide peer support and advocacy

Strengthen resourcing of community and sector leaders to ensure a sustainable support network for autistic people and their families

#### 4.7.3 Increase the representation of autistic people in leadership positions

Strengthen pathways for people with disability, including autistic people, to Victorian public sector bodies and committees

Support the I CAN Network to develop young autistic people between 15 and 24 years of age as speakers, mentors and emerging leaders

# Implementation

A committee comprising senior representatives of government departments will oversee the implementation of this plan. The Department of Health and Human Services will take on the coordinating role. The committee will draw on the expertise of a stakeholder implementation advisory group to guide the plan's implementation and monitoring.

# A process for reporting progress against actions

The Victorian Government's Office for Disability is a whole-of-government body that oversees and promotes disability inclusion policy. A key function of the office is to develop and manage state disability plans. Since 2018, state disability plan annual reports have been tabled in parliament, outlining progress against commitments and showcasing examples of innovation and good practice.

Reporting on the *Victorian autism plan* will form an appendix to each annual report for the next five years. The reporting will be used to show progress against commitments and showcase examples of good practice.

Annual reporting will also map progress against the 101 recommendations of the Parliamentary Inquiry into Services for People with Autism Spectrum Disorder. To promote efficiencies and partnerships across government, a number of recommendations have been bundled under the commitments of this plan. Mapping of commitments and recommendations will allow people to see how the actions we are taking align with those recommendations. This reporting will include public advice on early actions to support the plan that were funded and completed in 2018 and 2019. The first round of annual reporting will introduce the initial set of outcomes indicators and measures that will be used for this plan. Subsequent annual reporting will highlight available data against these indicators and measures.

# A process for refreshing actions

Many of the actions are already being implemented or will be implemented in the first few years of this five-year plan.

For this reason, it is important that this plan undergo a refreshment at its midway mark for the purposes of:

- identifying outcome areas that need additional focus
- identifying inquiry recommendations that need additional focus.

The refresh process will begin at the end of the second year of the plan, using existing whole-ofgovernment processes to engage all parts of the Victorian Government.

By the end of a six-month review and development process, a set of new or continuing commitments will be agreed, for publication in the third wave of annual reporting against the plan.

The refresh will also be used to make sure the *Victorian autism plan* can leverage the commitments and priorities detailed in the next state disability plan, which will operate from 2021 to 2024.

# **Appendix 1: Consultations**

The aspirations of the autism community in Victoria have guided development of this plan. Between February and April 2018, the Victorian Government held more than 20 consultation meetings and conducted an online survey of 787 people in the autism community.

### Workshops

The government held six workshops to hear from people in the autism community:

- education 15 February 2018
- health and mental health 21 February 2018
- employment and pathways to employment 1 March 2018
- housing, justice and parenting 6 March 2018
- diagnosis, and integrated and coordinated services – 14 March 2018
- rural and regional issues 5 April 2018.

These workshops were attended by autistic people; parents and carers; advocacy groups; peak bodies; disability service providers; health, allied health and education professionals; researchers; and representatives from Victorian government departments. In total, 115 people participated in one or more workshops, including about one in six who identified as autistic or as a family member of an autistic person. Key issues raised by participants across all the workshops included:

- the importance of engaging people with lived experience of autism in the planning and delivery of all services for autistic people
- the need to treat each autistic person as an individual, requiring personalised support and services at all stages of their life
- the importance of early diagnosis and intervention
- ensuring there is access to information on services and support that is appropriate in content and style for autistic people and their carers at all stages of life, particularly during transition points such as school entry and seeking or starting work
- increasing the understanding and capability of workforces that interact with autistic people
- ensuring that services provided to autistic people are integrated to meet their needs
- improving data collection on services needed by autistic people and the performance of those services
- increasing community understanding of the needs of autistic people.

Many of the workshop participants also commented on the value of having networks for sharing information, including the workshops as a valuable part of this information-sharing process.

# Targeted meetings and focus groups

The government conducted 14 targeted meetings and focus groups to gain a deeper understanding of issues affecting autistic people in Victoria. These included:

- participants at Araluen support service (facilitated by Amaze) 15 March 2018
- Behaviours of Concern Peer Action Group (facilitated by VALiD) – 15 March 2018
- participants at Annecto David House support service (facilitated by Amaze) – 19 March 2018
- Victoria Police Disability Portfolio Reference Group – 27 March 2018
- Olga Tennison Autism Research Centre 4 April 2018
- LGBTI+ issues (hosted by Spectrum Intersections) – 5 April 2018
- Victorian Children's Council 6 April 2018
- culturally diverse communities (hosted by Action on Disability within Ethnic Communities) – 11 April 2018
- Office of the Public Advocate 18 April 2018
- women and girls with autism (hosted by Yellow Ladybugs) 18 April 2018
- Commission for Children and Young People 20 April 2018
- Aboriginal communities (hosted by the Victorian Aboriginal Health Service) – 30 April 2018
- Office of the Disability Services Commissioner 1 May 2018
- members of the Victorian Public Service Employees with Disability Network (The Enablers) – 4 May 2018.

## Survey

Advisory group members distributed an online survey to enable a broader range of people in the autism community to have a say on the topics covered in the workshops. Of the 787 people who completed the survey, 116 (15 per cent) identified as an autistic person and 598 (76 per cent) as a family member or carer. Almost one-quarter (24 per cent) of respondents (189) were from a rural or regional area of Victoria.

Ninety-three per cent of respondents chose to provide information on the level of difficulty experienced or help needed doing various activities of daily living. This question was adapted from a standardised indicator of disability status developed at the Australian Institute of Health and Welfare. Fifty per cent of respondents indicated that they (or an autistic person they care for) had a limitation in one or more activities. This included 82 with profound limitation and 196 with severe limitation.

# **Appendix 2: Policy context**

This plan reflects other important reforms and strategies that aim to improve the quality of life for people with disability in Victoria. These are discussed below.

### **Parliamentary inquiry**

In June 2017 the Family and Community Development Committee of the Victorian Parliament tabled its *Inquiry into Services for People with Autism Spectrum Disorder: final report.* The inquiry was held over two years and included 154 submissions and 89 witnesses, as well as a study tour to look at best practice in other countries.

The report made 101 recommendations to improve supports, services and inclusion of autistic people. These recommendations set the foundation for this plan.

The government welcomed the report, investing \$22.4 million to take some immediate actions. These included:

- developing a public education campaign about autism
- supporting autistic people to transition to the National Disability Insurance Scheme
- strengthening support for autistic children in the early years and in the school system
- developing a responsive workforce to meet the diverse needs of autistic Victorians
- creating new sport and recreation opportunities for autistic Victorians
- strengthening support for autistic girls and women and autistic Victorians in rural and regional areas.

A significant number of autistic people, their families and supporters shared their knowledge and experience through the work of the inquiry. The *Victorian autism plan* acknowledges and draws on that body of testimony.

# Absolutely everyone: state disability plan 2017–2020

Absolutely everyone is the government's strategic policy on disability. It sets out the vision of an inclusive Victoria that supports people with disability to live satisfying everyday lives and participate on an equal basis with other Victorians.

Absolutely everyone provides the framework to implement, monitor and report on the Victorian autism plan. In particular it is the basis for the outcome framework, indicators and measures that structure and inform this plan.

'The social model seeks to change society in order to accommodate people living with impairment; it does not seek to change persons with impairment to accommodate society.'<sup>12</sup>

#### - People with Disability Australia

The state disability plan is also the Victorian Government's primary tool for implementing the National disability strategy 2010–2020 and meeting its responsibilities under the United Nations Convention on the Rights of Persons with Disabilities.

Absolutely everyone reflects a social model of disability. The social model recognises that while many people have additional physical or nonphysical requirements, it is only when a society's attitudes, environments and systems fail to accommodate these additional requirements that the concept of disability arises.

12 Sourced from the People with Disability Australia website <a href="https://pwd.org.au/">https://pwd.org.au/</a>.

#### Every opportunity: Victorian economic participation plan for people with disability 2018–2020

Every opportunity is the Victorian Government's economic participation plan for people with disability. It includes actions to improve the lives of Victorians with disability as workers, employers, entrepreneurs, investors and consumers. Some of the actions in *Every opportunity* specifically aim to increase the employment of autistic Victorians.

#### Victorian carer strategy 2018–22

The Victorian carer strategy is the first wholeof-government strategy that recognises and supports the important role of Victorian carers. Carers for people with disability are a core focus of the strategy.

The strategy aims to support carers where they need it most. Its five priority areas will support carers to:

- be healthy and well
- be engaged in education, employment and community
- access respite and other supports they need when they want them
- have less financial stress
- be recognised, acknowledged and respected.

The *Victorian carer strategy* has been developed with input from carers and peak bodies.

#### Victoria's disability abuse prevention strategy – dignity, respect and safer services

The disability abuse prevention strategy is part of the Victorian Government's response to the 2015–16 Parliamentary Inquiry into Abuse in Disability Services. It recognises the role service providers and the disability sector have in stopping abuse from happening and sets out strategies to build the capacity of people with disability to assert their rights and voice.

### **Education State**

Inclusive education is an important part of the Victorian Government's vision for Victoria as the Education State. The inclusive education agenda is strengthening the capacity of the Victorian education system to support students with disability and additional needs, including autism, to ensure these students participate, achieve and thrive at school.

### National Disability Insurance Scheme

The NDIS is a significant reform helping to change how disability is viewed and what people with disability can achieve with the right supports. Victoria is investing \$2.5 billion a year into the NDIS for disability supports.

Autistic people make up one of the largest groups accessing the NDIS in Victoria. However, there are a range of issues that are limiting the effectiveness of the NDIS for autistic Victorians.

The plan outlines how the Victorian Government will advocate with the Commonwealth and the National Disability Insurance Agency to increase the equity and accessibility of the scheme for autistic people.

The NDIS offers direct services to around 10 per cent of people with disability. However, people with disability who are not in the scheme need to access mainstream services that provide accessible and appropriately delivered services.

For this reason, the plan sets out actions that will make Victorian workforces and services more capable and responsive when meeting the needs of autistic people.

### **Royal commissions**

The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability was established on 4 April 2019 by the Governor-General of the Commonwealth of Australia. The inquiry will cover all forms of violence against, and abuse, neglect and exploitation of, people with disability, in all settings and contexts.

The Royal Commission into Victoria's Mental Health System is the first of its kind in Australia. It is a once-in-a-generation opportunity to accelerate improvements in access to mental health services, service navigation and models of care.

Both royal commissions address issues that directly affect many autistic Victorians. Accordingly, this plan sets out ways in which it will support the voice and advocacy of autistic people and their families.

### Family violence reform

The Victorian Government is committed to implementing all 227 recommendations of the Royal Commission into Family Violence. A key aspect of the government's family violence reform agenda is improving responses to people with disability experiencing family violence. Women and children with disability are disproportionately likely to experience family violence, and people with disability face additional barriers to reporting family violence and accessing support. *Everybody matters: Inclusion and equity statement* sets out the Victorian Government's long-term vision for creating a family violence system that is more inclusive, safe, responsive and accountable to all Victorians.

# **Appendix 3: Our engagement approach**

The government recognises that autistic people are experts in what is best for them. Many people, including autistic people, their families, supporters and service providers, contributed to developing this plan. We will continue to work with the autism community to implement the actions.

Our approach included working with an advisory group, holding workshops and community consultations and running an online survey (see Appendix 1).

## Stakeholder advisory group

The Victorian Autism Plan Advisory Group represents a range of autistic people, their families, supporters and service providers, with representatives from:

- Amaze
- Aspergers Victoria
- Association for Children with a Disability
- Autism Family Support Association
- Different Journeys
- I CAN Network
- National Disability Services
- Spectrum Intersections
- Victorian Advocacy League for Individuals with Disability (VALiD)
- Victorian Disability Advisory Council
- Yellow Ladybugs.

The group has provided expert advice on developing the plan, arranged workshops with autistic people and their families, and informed organisations and individuals about the consultation process.

# Stakeholder advisory group membership

Karen Dimmock Chief Executive Officer, Association for Children with a Disability

**Tamsin Jowett** President, Aspergers Victoria

**Anne Kavanagh** Member, Victorian Disability Advisory Council

**Katie Koullas** Founder and Chief Inspiration Officer, Yellow Ladybugs

Dariane McLean Advocate, Victorian Advocacy League for Individuals with Disability

**Sarah Fordydce** Policy Manager – Victoria, National Disability Services

Mellem Rose Spectrum Intersections

Fiona Sharkie Chief Executive Officer, Amaze

**Michael Tucker** President, Autism Family Support Association Inc.

**Chris Varney** Founder and Chief Enabling Officer, I CAN Network

**Melinda Spencer** President, Different Journeys

## Survey

People in the autism community contributed to the plan through an online survey. The 787 participants included 117 autistic Victorians and 598 family members or carers. Regional Victoria was well represented, with almost one in four participants from rural or regional areas.

### Workshops

Between February and April 2018 we held six themed workshops, each covering a topic such as diagnosis, integrated and coordinated services, school education, health and mental health, services for autistic adults, and rural and regional issues.

Participants provided expert advice on what is and is not working for autistic people and their families and how to include and support them. Participants included autistic people, family members, carers and supporters, autism organisations and service providers, disability service providers, health and allied health professionals, education professionals and researchers. A total of 115 people participated in one or more workshops.

# Other community consultations

Meetings with organisations and focus group discussions also helped us to develop actions to meet the diverse needs of autistic Victorians. This included organisations representing autistic women and girls, Aboriginal community-controlled organisations, communities from diverse cultural backgrounds, and LGBTI+ communities with autism.

We held focus group discussions with autistic adults at two day-services for people with disability, and with parents of autistic adults with behaviours of concern. These discussions helped us better understand the needs of autistic Victorians with complex needs and their families and carers.

