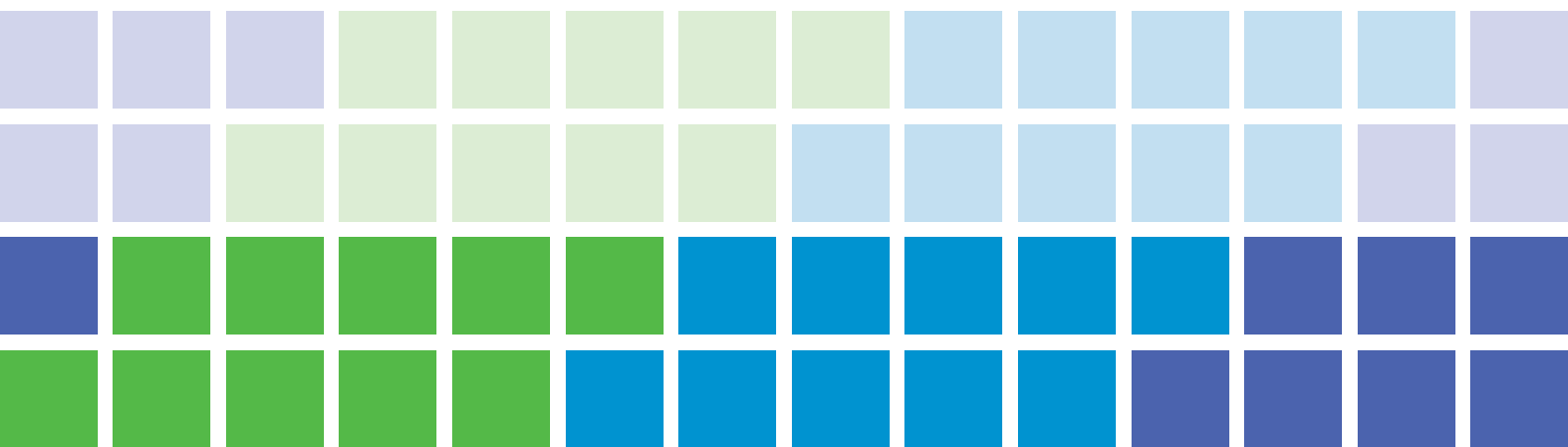
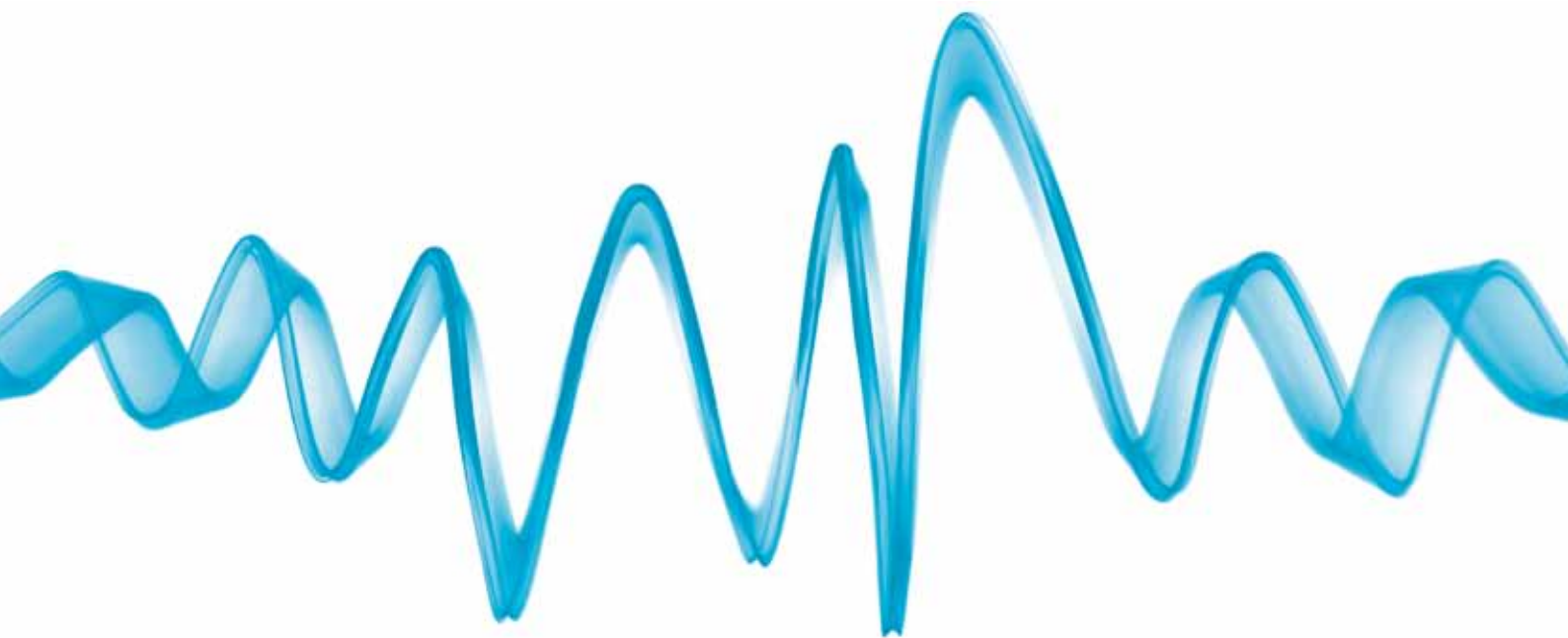


# Autism State Plan







# Autism State Plan

May 2009



If you would like to receive this publication in an accessible format please telephone 03 9096 0526 or email [autismstateplan@dhs.vic.gov.au](mailto:autismstateplan@dhs.vic.gov.au)

Published by Strategic Projects Branch, Portfolio Services and Strategic Projects, Victorian Government Department of Human Services

© Department of Human Services, Victoria 2009

This publication is copyright. No part may be reproduced by any process except in accordance with the provisions of the Copyright Act 1968.

Also published on [autismstateplan.dhs.vic.gov.au](http://autismstateplan.dhs.vic.gov.au)

Authorised by the State Government of Victoria, 50 Lonsdale Street, Melbourne. Printed on sustainable paper by Big Print, 45 Buckhurst Street, South Melbourne 3205

## Ministerial Foreword



At the last State election, the Victorian Government committed to develop an Autism State Plan. In developing the Plan, we worked in partnership with Autism Victoria. From the outset, our shared aim has been to develop new and better approaches to meet the growing and complex needs of people with an

Autism Spectrum Disorder (ASD). The government appreciates the energy and commitment provided by Autism Victoria and its representatives in this process.

As Minister for Community Services and lead minister for the Autism State Plan, I am very pleased to release the Plan. The Plan provides us with a vision for the next 10 years during which time we will work closely with families and the broader community to achieve its goals. The contributions of approximately one thousand Victorians, gathered through the extensive statewide consultation undertaken across metropolitan and regional Victoria in October and November 2007, constituted a major input into the Plan's development. Information from the consultation was complemented by a focused examination of local and international ASD research and policy. The response by Victorians throughout the consultation demonstrates the importance placed on improving the way we provide support to people with an ASD in our community and ensures that the Plan has been informed by the knowledge of those with direct experience of ASD.

In December 2008, the government acted to resolve an important issue that was raised by Victorians during the statewide consultation process. By acknowledging that ASD is a neurological impairment, all people with an ASD can be considered for entry into the disability services system. Previously, people with an ASD who did not have an intellectual disability could not access Department of Human Services disability services.

The release of the Plan signals the conclusion of its development and heralds the next stage: implementation. Six priority areas are identified in the Plan which will be addressed in the short, medium and longer term of the Plan's implementation:

1. Make it easier to get support
2. Strengthen the ASD expertise of the workforce
3. Extend and link key services and supports especially during transition
4. Enhance and provide appropriate educational opportunities
5. Facilitate successful participation in the community
6. Develop a robust evidence base about ASD

People with an ASD, their families and carers want good information, practical support and services they can trust. The Plan responds to the issues and concerns of the people with whom we consulted, recognising that ASDs, although sharing core features, are diverse and that they are lifelong conditions. The Plan has a whole of life focus and identifies priority actions that will make a difference in the short term with work continuing during the implementation stage to progress activity in other areas into the future.

Working closely with Autism Victoria to develop the Plan has proved very beneficial. The government is now looking forward to working with people with an ASD, their families, other stakeholders and the broader community to implement the Plan's priority actions.

I take this opportunity to thank those people who contributed to the Plan's development, including all those who participated in the statewide consultation and the representatives of Autism Victoria, who provided valuable insights and advice throughout the development of the Plan.

I commend the Plan to you.

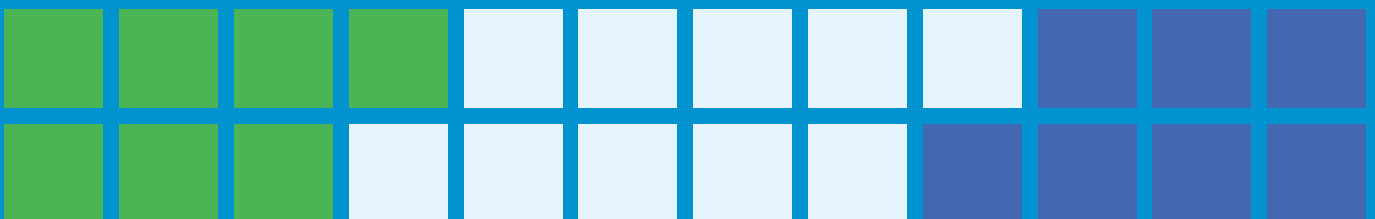
**Hon Lisa Neville MP**  
**Minister for Mental Health**  
**Minister for Senior Victorians**  
**Minister for Community Services**

My son was once treated like a 'terrorist' and was suspected of being a 'killer' child.

Professionals who know and understand ASD have taught me strategies I now use everywhere... and I am thankful for their insight, support and continued care.

My son has learned how to behave without aggression at home and on a footy field, has played for an U10 team at 7, and won an inspiration award for being so enthusiastic and determined. I am so proud. Thanks also to a dedicated footy coach.

Parent of a 7 year old boy with Asperger's Syndrome



## Representation from Autism Victoria

The government appreciates the energy and commitment provided by Autism Victoria during the process to develop the Autism State Plan (the Plan). Throughout the partnership, Autism Victoria has provided strong representation on behalf of people of all ages with an ASD, their families and carers. Particular priority areas that Autism Victoria has advocated include:

- Better public understanding of ASD, its distinctiveness and diversity.
- Access for all people with an ASD to a broad range of government services, in particular disability services.
- Targeted training and information for the professionals who work with people with an ASD, priority sectors being early childhood and early childhood intervention services, government and non-government education services, support staff in disability services, Home and Community Care (HACC), Technical and Further Education (TAFE) and in employment settings.
- Improved support across the whole life course, especially at times of transition during childhood, adolescence and adulthood into older age.
- Equal access for all with an ASD to support services and expertise in government and non-government schools.
- Greater effort to make all schools 'ASD friendly' and ensure all students with an ASD have equal opportunity to access appropriate and inclusive education settings.
- Helping families, including siblings, who are isolated, socially or geographically, and in greatest need of support.
- Helping people with an ASD live a full life in adulthood, including meaningful participation in society inclusive of work, leisure, recreation and relationships.
- Reducing waiting times for all services, including diagnosis, early intervention and disability support services.
- Making it easier for people with an ASD, their families and carers to access information (through local service providers or via weblinks), services and support that are timely, accurate and useful.
- Having a key government sector to fulfil a leadership role in taking responsibility for the autism spectrum community and their needs.
- Having a plan that makes a real difference to the quality of life for people with an ASD, their families, including siblings, and their carers.
- Having accurate data about people with an ASD, including the number of people with an ASD, where they are, the types of services they access, the types they are unable to access, and data about various cohorts, such as people with an ASD in, for example, the education system, youth justice and so on.



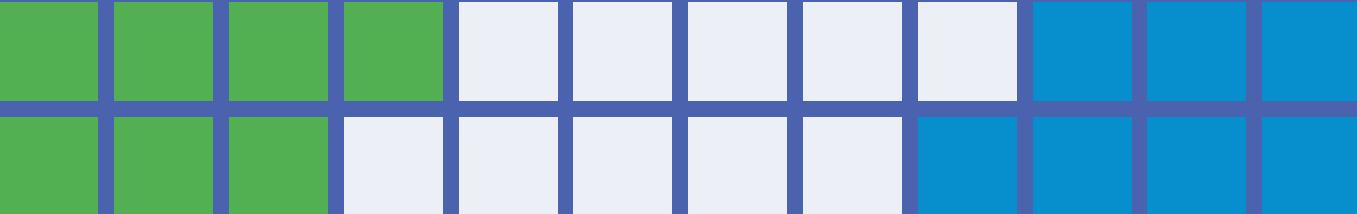


# Contents

Minister's Foreword	3
Representation from Autism Victoria	5
Introduction	9
The need for a plan	9
Developing the Plan	9
Policy and service context	9
About ASD	11
What is ASD?	11
How common is ASD?	11
Life journey with an ASD	14
The Autism State Plan	20
A vision for support	21
Achieving the vision	22
Priority areas for action	22
Implementing the Plan	35
The Action Schedule	36

At my school I didn't like the uniform because the colours were navy, blue and green. The only way that I could cope with it was by wearing red socks.

Young man of 18 with Autism



# Introduction

## The need for a plan

In Australia and overseas, ASDs are becoming more prevalent and demand on services and support is growing. The development of an Autism State Plan acknowledges that ASDs have particular features that distinguish them from other conditions.

The distinctive features of ASD can make diagnosis complex. Diagnosticians need expertise and experience in diagnosing ASD and families need support during the diagnostic process because it can take time and require multiple assessments.

We know that people with ASDs have varied and complex needs and many require support across their life course, from formal and informal services and from their families and communities. The impact on families caring for a person with an ASD is significant and it is not uncommon for families to have more than one member with an ASD.

ASDs are poorly understood conditions in the community, including in culturally and linguistically diverse and Indigenous communities. There is a good deal of misinformation. Improving community understanding and awareness of ASDs and the impact of these conditions will have benefits for people with an ASD and their families as well as for the broader community.

The development of the Plan acknowledges that present services were planned for lower ASD prevalence and are now under significant pressure. Future service planning requires a better understanding of service demand trends and the service needs of people with an ASD and their families over the life course.

## Developing the Plan

In its 2006 election policy, *Addressing Disadvantage*, the Victorian Government undertook to:

... develop an Autism State Plan in partnership with Autism Victoria, to build new and better approaches across government for meeting the growing and complex needs of people with autism and Autism Spectrum Disorders

Since then, the Department of Human Services (DHS), the Department of Education and Early Childhood Development (DEECD), and Autism Victoria ('the partners') have worked together to fulfil the government's commitment. A statewide consultation process was undertaken to ensure that the Plan reflects the views and experiences of people with an ASD, their families and carers, service providers, academics, teachers, doctors and others. In total, 252 written submissions from rural and metropolitan areas were received in response to the *Autism State Plan Consultation Paper*. People with an ASD, families

and carers, service providers and service organisations were all represented in these submissions.

In addition, a series of 23 forums was held across metropolitan and rural Victoria. More than 720 people attended, including people with an ASD, family members and carers, service providers, teachers, doctors, researchers and others.

As well as hearing from this broad range of Victorians, national and international ASD research, policy and practice has been examined to inform development of the Plan.

A number of people with an ASD, family members and carers contributed 'personal perspectives' during the consultation. Personal perspectives are written pieces that tell of the achievements and efforts of people with an ASD. With permission, sections have been taken from the personal perspectives and submissions for inclusion in the Plan.

## Policy and service context

### Service system

In Victoria, as in other developed societies, there is a complex arrangement of services that people may need over a lifetime. Public and private services make up the formal part of the service system, which complements the informal care and support provided by families, individuals and communities.

The State Government provides public services in health, mental health, disability, justice, family services and education. Some services are provided on a universal basis, some are general, while others are specialist. Many services are available in the local community, while specialist and tertiary/acute services are often only available in major cities or towns. Except for universal services, access to other publicly provided services is limited to identified priority groups.

People with an ASD and their families, like other Victorians, may need services from the universal or general service system, but they may also need specific programs or specialist services.

Disability Services Division of DHS provides services and support for eligible people using an individualised, person-centred approach. From December 2008, all people with an ASD can be considered for access into the disability services system.

DEECD offers early intervention, special education schools and support in mainstream schools for eligible students. Support is targeted to those most in need.



The Commonwealth Government also provides public services in Victoria, for example, general and specialist medical practitioners via Medicare. Other Commonwealth funded services complement or augment those provided by the State Government.

The complexity of the Commonwealth and State service systems can create difficulties when people with an ASD and their families try to find information and services. Collaboration between the different levels of government through the Council of Australian Governments aims to reduce this complexity.

Local government also provides public services to residents of a municipality, including Maternal and Child Health and HACC services.

Alongside government service provision is a diverse range of private services covering most professional specialities, as well as a range of services not provided by governments.

Community organisations, support groups and faith based groups, philanthropic trusts and others all contribute to the fabric of support and service that may be available to individual and families locally.

### Policy context

Over the last ten years there have been significant policy developments in Victoria which have led the way to the development of an Autism State Plan. Prominent amongst these policy developments are *Growing Victoria Together* (2003), *The Victorian State Disability Plan 2002-2012, A Fairer Victoria* (2005) and *The Charter of Human Rights and Responsibilities Act 2006*.

Other relevant State and Commonwealth policy developments include:

- Review and redevelopment of *Support for Children with a Disability and their Families – Final Report*
- *The Blueprint for Education and Early Childhood Development*
- *Because Mental Health Matters: Victorian Mental Health Reform Strategy*
- The Victorian Disability Employment Strategy
- National Reform Agenda – Victoria's Plan to Improve Outcomes for Children
- The National Disability and Mental Health Employment Strategy
- The Commonwealth Government's Helping Children with Autism package.

Evidence has directed a shift in focus toward the early childhood period as a critical time for intervention. Similarly, recognition of the benefits to society of participation by all through work or a meaningful occupation has reduced barriers to social participation. Participation in society adds to the quality of life by improving material wealth through employment and personal wellbeing through a greater connection to others and engagement in leisure, study and recreation activities.

Increasingly, a lifetime perspective is being adopted to guide interventions as the health and economic impacts of lifelong developmental conditions such as ASDs are better understood.

### International policy approaches

There is general acknowledgement across jurisdictions that 'more could be done' to support people with an ASD to realise their potential to contribute to society, and to support families as the principal caring unit. The priority areas listed below are a summary of key issues identified in the documents reviewed:

#### International policy: priority areas

1. Organising diagnostic assessment and early intervention services to maximise individual and family outcomes
2. Developing regional mechanisms to concentrate expertise for strategic, education, training, research and service support purposes
3. Developing and equipping the workforce
4. Providing more assistance for individuals and families to find the services they need
5. Providing evidence based interventions in early childhood and education services
6. Providing educational options, increasing the support available and improving teaching approaches in primary, secondary and post secondary educational settings
7. Focused effort around times of transitions
8. Appropriate support to the individual and/or family during adulthood: accommodation, employment, leisure, health care and mental health care
9. Raising awareness and educating the public
10. Investing in research including into incidence/prevalence; the development of data systems

## About ASD

### What is ASD?

Autism Spectrum Disorders (ASDs) are neurodevelopmental disorders that cause substantial impairments in social interaction and communication and are associated with unusual behaviours and interests. Although not officially defined in any international medical classification code, the term 'Autism Spectrum Disorder' is commonly used to encompass Autistic Disorder, Asperger's Syndrome, and Pervasive Developmental Disorder – Not Otherwise Specified (also known as Atypical Autism). Some people with Autistic Disorder with an IQ in the typical range may also be described as having High Functioning Autism (HFA). ASDs are described according to a spectrum, with varying degrees of pervasive impairment that range from mild to severe.

The cause of ASD is unknown. There is no medical or genetic screening or diagnostic laboratory test for ASDs; diagnosis is based on the presence of particular behavioural patterns. ASDs can be identified from early childhood onwards and affect a person throughout their whole life. ASDs occur in all racial, ethnic and socioeconomic groups and are four times more likely to occur in boys than in girls. Many people with an ASD have unusual ways of learning, paying attention and reacting to different sensations. Their thinking and learning abilities vary, with approximately 80 per cent having an associated intellectual disability and 20 per cent with intelligence within the normal range. Although people with an ASD exhibit qualitative impairment in communication and social interaction, and restricted repetitive and stereotyped patterns of behaviour, interests and activities, they can also present measurable and admirable differences in perception, attention, memory and intelligence.

### How common is ASD?

Until the 1980s and 1990s, childhood ASDs were considered to be uncommon. However, successive studies have reported progressively rising prevalence rates.

While there is no confirmed prevalence data for Victoria, the La Trobe University report, *Autism in Victoria*, found a prevalence rate of diagnoses of ASD or suspected ASD in Victoria (as of June-July 2002) in the 0–6 year age cohort estimated at 27 per 10,000.<sup>1</sup> A recent Australian study, the *Prevalence of Autism in Australia*, commissioned by the Australian Advisory Board on Autism Spectrum Disorders, found an estimated prevalence of ASD across Australia of 62.5 per 10,000 (1 in 160) for 6–12 year old children.<sup>2</sup> This level of prevalence is comparable to recent international studies.

1 Crewther, S., Goodyear, M., Bavin, E., Lawson, M., Wingenfeld, S. & Crewther, D. (2003). *Autism in Victoria: An investigation of prevalence and service delivery for children aged 0-6 years* (unpublished report funded by the Victorian Department of Human Services).

2 MacDermott, S., Williams, K., Ridley, G., Glasson, E. & Wray, J. (2006). *The prevalence of an ASD in Australia. Can it be established from existing data?* Australian Advisory Board on Autism Spectrum Disorders.

My whole self is like a big bowl of tangled spaghetti that is nervous all the time. Depending on what is happening around me the spaghetti can get more nervous.

I think I have many layers:

The nervous spaghetti that doesn't understand or like new things.

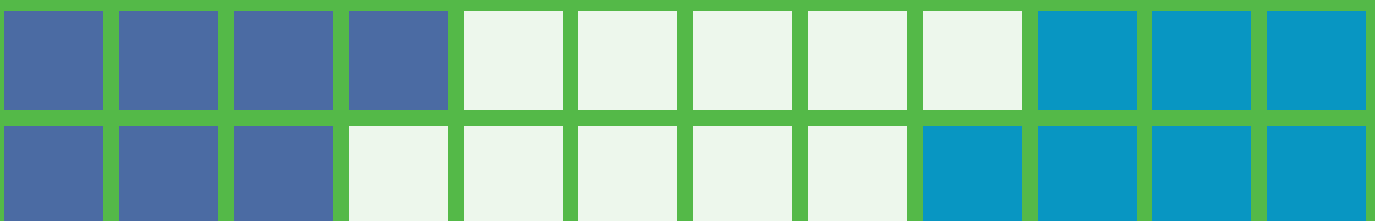
The safe spaghetti at home.

The smart spaghetti who can see the numbers in his head to maths questions and the percentage shots in tennis.

The biggest layer of all is the one that doesn't understand people and why they say things, but mean something else.

I don't think I'll ever understand that. Mum and other people tell me that I am like this because of my autism. I hate my autism sometimes, especially when the tangled spaghetti is very nervous.

15 year old with Asperger's Syndrome





## Life journey with an Autism Spectrum Disorder

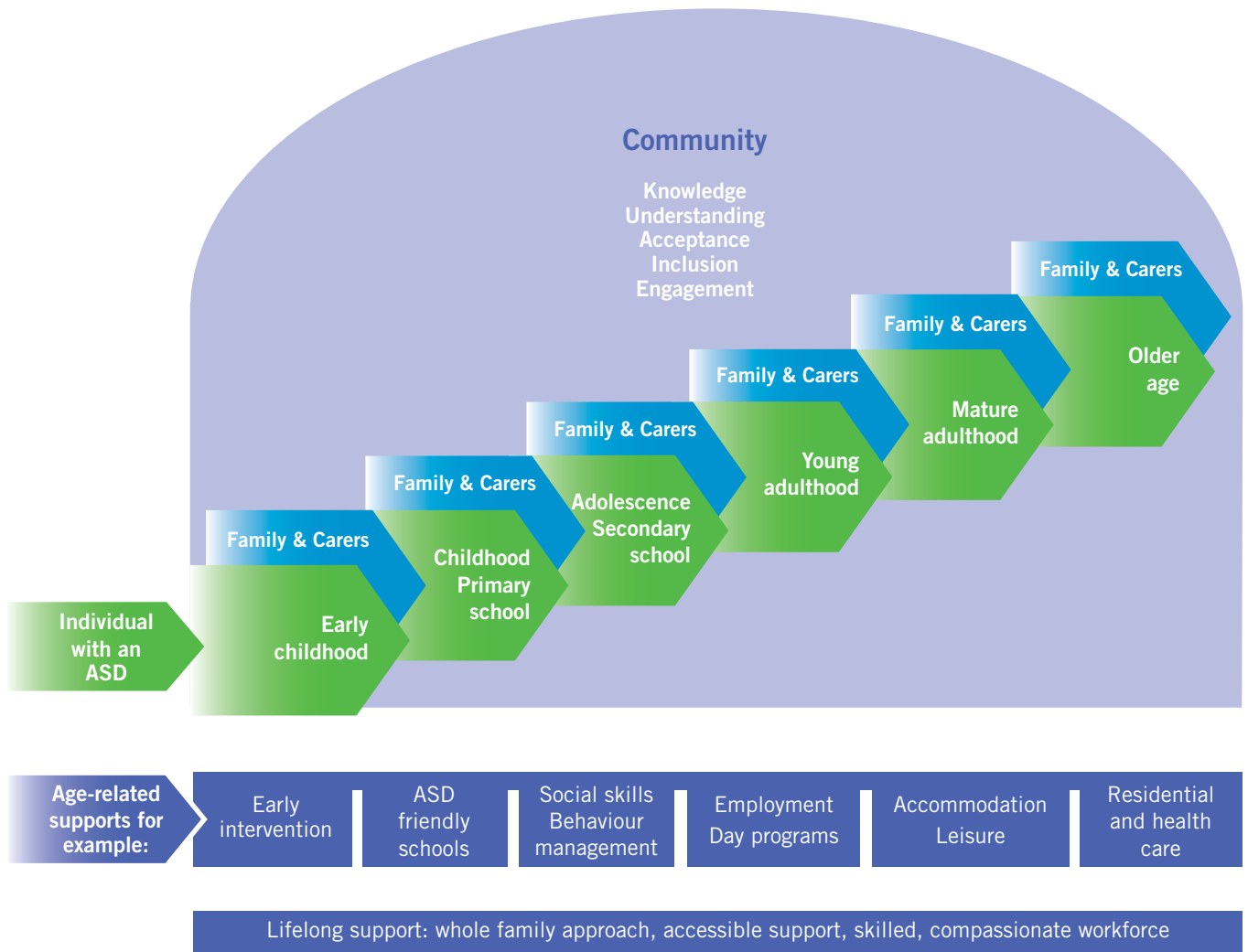


Figure 1: Life journey with an ASD – key issues for the individual and family

Figure 1 above outlines some of the different support needs of people with an ASD, their families and carers over the course of a lifetime. It shows that most often the person with an ASD is cared for by family members or carers in a community setting and during each 'life stage' may engage with a wide range of services and supports. The following section gives an overview of the issues that people with an ASD, their families and carers may face.



## Life journey with an ASD

I was relieved to hear it, not upset. The diagnosis was an answer and a structure in which to help my beautiful daughter.

My son wasn't diagnosed with High Functioning Autism until he was 14. I knew there was a problem which appeared to start at the age of 3.

### Concerns and issues for families

The pathway from first concerns to diagnosis of an ASD in early childhood or later can sometimes be straightforward and sometimes not. Waiting lists for assessments and diagnosis can make this period very difficult.

The impact of the diagnosis on parents, siblings and others can be significant as families reshape their expectations and try to make sense of what the diagnosis means in the present and the future: What school will he go to? Will she always be non-verbal? Will he be able to get a job? Who will look after him when I die?

In some sections of the community the concept of disabling conditions is different and language or cultural differences can further isolate and make the post-diagnostic period very difficult.

Managing a family and the needs of other family members while trying to find information and support following diagnosis can cause great anxiety and stress for parents. While in some situations concern can extend to involve the broader family and friends, in others isolation from the broader family, friends and local community can occur.

In seeking the best for their child and to avoid long waiting lists, families may take on added financial stress as they pay for therapy or seek an educational approach that they believe will help their child. At the same time, the capacity to earn may be limited as a parent reduces employment to care for the child, 'home-school' the adolescent or supervise the dependent adult. All this will be occurring while parents are trying to manage difficult behaviours of the child or young person, attend to the needs of other children and 'make ends meet'. Often families experience a lot of stress and anxiety, problems with relationships and isolation from others. Difficulties finding the right services and people to advise and help adds to the burden.

For others, diagnosis may not occur until adolescence although there may have been concerns much earlier. Some people with HFA or Asperger's Syndrome may not be diagnosed until adulthood and may have experienced many years of anxiety and social and relationship difficulties before the diagnosis is confirmed. For adults this is complicated by a lack of professionals skilled in adult ASD diagnosis. People diagnosed as adults talk about the negative impact of their condition on their relationships, problems looking after themselves on their own and difficulties getting and keeping a job.

Along with prompt, specialised, quality therapeutic intervention and support services, people with an ASD and their families may need:

#### Someone to help sort out what to do, to give good advice

This could be a general practitioner (GP), a friend, a professional involved with the diagnosis, school staff, Disability Services staff or information from a disability provider such as Autism Victoria, the Association for Children with a Disability or the Association for Disabilities within Ethnic Communities.

#### Good information

This is information that is trustworthy (backed by research), easy to get, is available in a range of community languages and is useful.

#### Someone to talk to about worries, anxieties or problems

This could be a counsellor, a GP, a friend, a church leader, other people with a family member with an ASD.



### Understanding from others

Whether from peers at school or in the workplace, family members or others in the community, understanding, respect and acceptance are important,

### Support needs across the life course

The type and amount of support people with an ASD and their families need will vary and may change over time. Whether diagnosis is early in life or later, support should help the person with ASD, their family and carers live their lives as fully as possible.

With an early in life diagnosis, early intervention for the child and assistance for the family to help them manage are key aspects of support.

Young children with an ASD may be able to access extra support through the Kindergarten Inclusion Support Service (KISS). Students with an ASD can be supported in a variety of school settings, including integration into a mainstream school, enrolment in a special school or in one of five schools that specialise in the support of students with ASD. During the primary and secondary years if a student with an ASD attends a government school they may be eligible for additional support through the Program for Students with Disabilities (PSD).

When diagnosis is made later in life, different types of support are required by the person with an ASD and others, including their parents, partner or employer.

Services provided by governments, community service organisations and the private sector overlay the informal support provided by families, individuals and groups, such as clubs, faith based communities and local networks.

Supports that help are:

#### Time out

Respite might be provided to young people with an ASD in the form of camps, social groups, Big Brother (or similar program) or, alternatively, provided by friends and family.

#### Practical help and advice

This may be provided by family and friends, local support groups, resource centres and ASD information and support organisations like Autism Victoria. The many professionals and support workers that people with an ASD, their families and carers have contact with over time can be important sources of advice, and provide assistance in their professional capacities.

#### Strategies to manage

Some parent programs are considered useful by parents. For young people and some adults with an ASD, strategies learnt through social skills programs, including day programs, can help with day-to-day living.

#### Confidence in the workers and professionals

Knowing that professionals and workers are knowledgeable about ASD, are competent, interact respectfully and employ appropriate strategies with the person with an ASD is an important form of indirect support to families.



## Age related and other transitions

Change is difficult for people with an ASD. Unexpected events, a change in routine, altered environments and interaction with new people, can all create extra stress and anxiety, which is reflected in difficult behaviours or a period of regression.

Planning and good preparation are key strategies that help people with an ASD, their family and carers during times of transition.

Change occurs across the lifespan with some obvious transitions, including starting school, and moving from primary to secondary school. Puberty is also a critical time and can be complicated for the person with an ASD, their family and carer due to the combination of more complex behaviour, increased physical size of the young person and sometimes the emergence of secondary mental health problems.

Emerging challenges for the young person with an ASD could include domestic violence, self-destructive behaviours such as self-harming and suicide, interaction with police and the justice system as either perpetrators or victims, and, in some situations, use and abuse of alcohol and drugs.

The transition from a Special Developmental School (SDS) or a secondary school into an adult occupation, such as a day placement or TAFE program, is another major change that can create great anxiety and stress for the person with an ASD and uncertainty for the family as routines alter. Other major transitions include the move into an employment program or job where the person will have to manage the demands of the workplace, may have to negotiate public transport, will be involved in developing relationships with others and may need to learn to live independently.

Little is known about older age transitions as people with an ASD may interact more frequently with the health system and require care from the aged care sector.

Managing life changes can be more successful for people with an ASD and their families when there is:

### Planning and preparation for change

Whatever the change, developing a plan to support the person with an ASD and the family is very important. Plans specify the actions that need to happen. Parents often take on a lot of this work on a day-to-day basis but there is an important role for professionals and workers. Families and carers can better prepare the person with an ASD when they are well informed about the new environment. Making links and visiting a new environment can be helpful when preparing for transition. Clear communication between those previously involved and those in the new situation with family and carer involvement is crucial to ensure continuity.

### Support during change

Extra support is needed to help the person with an ASD and their family. Increased anxiety, regression due to behaviours or a change in the level of engagement are not uncommon and may create extra demands and stress for the family and carers. Adjustment can take time. Understanding from others involved and practical support, including increased time for planning, is needed.

I learnt by myself to be independent, camping in caravan parks with phone calls to mum and dad... distant memories of school lessons about independence, to guide me when a sticky situation occurs.



The local mainstream school has embraced our son and cheers him on as he runs last in every race... Our little 'runner' needs fencing at the school and we have just achieved a grant to help.

## Engagement with education, training and learning for life

Pathways through schooling can be different for children with an ASD. Some start with an early education program in a special school setting; others attend kindergarten and undertake primary and secondary schooling in the mainstream system with assistance from DEECD programs such as KISS and the PSD. Some families home school their child. In whatever setting, each child will need different types and levels of support during their education.

Young people with an ASD have a number of pathways for further education and preparation for adult life, including vocational training, work placements, day programs, TAFE and university.

Educational outcomes for people with an ASD can be influenced by:

### 'ASD friendly' educational environments

An ASD-friendly school is one where:

- educational staff, including student support services officers and teacher aides, are knowledgeable about ASD. Children and young people with an ASD are accepted and assisted to realise their potential.
- the child or young person's potential vulnerability is recognised
- the child or young person is protected and treated with respect, and their dignity is safeguarded
- parents are invited to work in partnership with education staff
- there is some flexibility regarding the range of educational options and curriculum
- appropriate teaching strategies are employed.

### Education options

While there is ASD educational expertise in specific regional areas and parts of Melbourne, having ASD expertise available throughout the state would assist.

### Support for young adults

Good support at TAFE, university or in vocational training settings and staff who understand can influence the achievements of young people with an ASD. Opportunities to link up with others in their adult environment are valued by young adults with an ASD.



I hope our community will become more educated about autism and embrace people with autism and their differences and eccentricities. Now we are trying to make our children with autism blend in more so they don't get bullied or ostracised but it would be a lot better if they were allowed to be themselves.

I have Asperger's Syndrome and I have found it very difficult to get support in the workforce due to lack of understanding. I have trouble in work conditions. I get distracted easily by noise and conversations... It's very important to train employers and employees about autism and Asperger's Syndrome.

## Community living

Parents and siblings of a person with an ASD may not be able to participate in usual recreational and leisure activities and may become isolated. This can be due to the narrow interests of the person with an ASD, sensory problems, difficulties in crowds, unwillingness to participate or the lack of understanding and acceptance by others.

Participation in the workforce for parents or family members can be limited because of caring responsibilities. As a result, the person with an ASD and their family may be excluded from participating in community life. This isolation can continue over the lifespan.

Finding a place in society is often made up of a cluster of achievements that may be taken for granted. For many people with an ASD, achievements often require the assistance of others and are hard won. Some people with HFA or Asperger's Syndrome acknowledge the difficulties associated with forming and maintaining relationships with others, having and keeping a job, and achieving a level of independence.

The following can help:

### Being able to participate – being included

Participation for people with an ASD and family members will be improved when there is greater community knowledge and understanding of ASD, and better supports to ensure that those of all abilities can participate in the life of the community.

### Learning skills for life

A level of independence is a central part of adolescent and young adult learning. Opportunities to develop social and life skills with the support of trusted family and friends is important.

### Timely, planned support

People with an ASD may need support to maintain their participation in work, recreation and leisure activities or to manage in an accommodation setting.

### Accommodation and the longer term

Parents who have a child with an ASD may have to provide and/or plan for their child's long term accommodation and care.

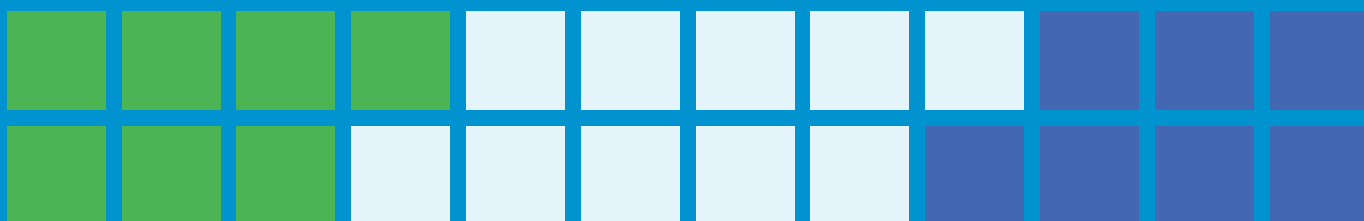
After my schooling years, I undertook an Advanced Diploma of Music and enjoyed the course as music is one of my interests and I was amongst like minded people.

After this, I joined up with the Futures for Young Adults program and they were of great help to me in seeking work.

I'm now enjoying working and being involved in a number of social groups.

In the past, I wished that I could be like people without disabilities and not have this condition, but now I'm proud to be a person with Asperger's and have lived life as I have done thus far, and I know that there are many more experiences worth looking forward to.

24 year old with Asperger's Syndrome





# The Plan

**Vision:** All People with an ASD and their families are supported to fulfil their maximum potential, enjoy life and contribute to their community.

## Guiding principles

Lifelong conditions

Diversity of ASD

Respect

Individuals and families have valuable knowledge to inform services

Participation

Support should help people reach their potential, and foster the wellbeing of family and carers

Priority to those particularly disadvantaged

Encouragement to speak up and make own decisions

Support based on sound evidence

## Implementation of the Autism State Plan

Whole of government approach

Stakeholder input

### Priority Area 1

Make it easier to get support

### Priority Area 2

Strengthen the ASD expertise of the workforce

### Priority Area 3

Extend and link key services and support, especially during times of transition

### Priority Area 4

Enhance and provide appropriate educational opportunities

### Priority Area 5

Facilitate successful participation in the community

### Priority Area 6

Develop a robust evidence base about ASD



## A vision for support

All people with an ASD and their families are supported to fulfil their maximum potential, enjoy life and contribute to their community.

### Principles

The Plan has been developed guided by the following principles:

#### Principles

- Autism Spectrum Disorders are lifelong conditions. People with these conditions may need a variety of supports throughout their life.
- ASDs include a wide spectrum of disorders. People with an ASD, their family and carers have a diverse range of experiences, skills, strengths and needs.
- Respect for the person, their family and carers, which includes respect for the individual's culture and dignity at all times.
- People with an ASD, their families and carers have valuable knowledge, experiences and perspectives that should be used in developing services, information and professional development approaches.
- People with an ASD should be able to participate and be included in the types of activities that other people participate in, such as school, leisure and work.
- Support should help people with an ASD reach their full potential; it should also look after the wellbeing of the family and carers.
- People with an ASD, their families and carers should be able to access support. Priority should be given to ensuring disadvantaged individuals do not miss out.
- Support should encourage people with an ASD, their families and carers to speak up, say what they want and make their own choices and decisions.
- Support should be based on sound evidence.

### The Plan's aims

This Plan aims for a service system of support across the lifespan to improve the 'quality of life' of people with an ASD, their families and carers. Support will be provided by government funded services, private providers, families and carers and the wider community working together.

Support services will be delivered in a timely manner, recognising the diversity and distinctiveness of people with an ASD and their families, inclusive of their cultural and linguistic preferences whether the person lives in supported accommodation, at home with family or independently.



Support provided to people with an ASD, their families and carers will be easy to access with strong links between services. Information will be accurate, timely and useful, with provision made for those whose first language is not English. Most importantly, services will be of high quality where service delivery is informed by evidence. Innovation will be encouraged with outcomes evaluated and learnings shared. Preparation of a skilled and compassionate workforce that can interact respectfully with families and safeguard the dignity of the person with an ASD, at all times, will be assured.

It is recognised that people with an ASD, their family and carers value support that is provided in a culturally competent manner. Over the life course, it is likely that the mix and intensity of support will vary. The types of support required could include:

- early intervention and diagnosis
- information and early support
- planning and support for key transitions
- education options that maximise the student's potential
- counselling/guidance/behaviour support
- respite
- meaningful occupation and work
- social support and help to participate fully in all aspects of life
- supported accommodation.

### Achieving the vision

To achieve this vision, we need the right mix of supports, delivered in a timely fashion by a skilled workforce alongside families and communities. We also need to ensure that the broader community is supportive and understanding of those with an ASD and the very particular stresses and challenges that families confront.

Feedback received during the extensive statewide consultation has helped to distil six priority areas for action:

### Priority areas for action

1. Make it easier to get support
2. Strengthen the ASD expertise of the workforce
3. Extend and link key services and supports, especially during transition
4. Enhance and provide appropriate educational opportunities
5. Facilitate successful participation in the community
6. Develop a robust evidence base about ASD

The following section details the priority areas for action and provides an explanation as to why they are priorities. Under each priority area is an aim and examples of how the aim could be achieved. Information about current government services and supports relevant to each priority area concludes each section. Specific actions relating to the priorities are listed in the Action Schedule on pages 38-41.



## A. Make it easier to get support

**Aim:** That all people with an ASD, their families and carers have ready access to the advice and support they need.

### Why is this a priority?

People with an ASD may require service responses that span many sectors over time.

Research tells us that intervention early in life can give a person the best chance. For intervention to occur, systems must be in place for early identification of symptoms and diagnosis of ASD. Some family members talk of difficulties in finding and accessing services, long waiting lists and frustration with the different eligibility criteria between services.

Service access can be particularly difficult in rural areas where there are greater distances to public services and a lack of private providers. Families report high costs associated with the use of private services and travel.

The impact of caring for someone with an ASD is significant. There can be great stress associated with the caring role. Families and carers say that parent and peer support programs, respite and counselling can help them manage their caring responsibilities. Improved community understanding can also reduce feelings of isolation. For people from refugee, immigrant or other culturally diverse communities, isolation can be more intense.

It is well recognised that access to trusted and reliable sources of information in appropriate formats and languages can help people to cope in times of crisis. People with an ASD, their families and carers need information about ASD, about how to access services and supports, and how to best help the person they care for.

Participants in the consultation reported that they access information from a range of sources and that information is variable in quality and usefulness. Sometimes families come across information that can be misleading, with the Internet being a major source of unscrutinised material. For those whose first language is not English, accessing trustworthy information in their own language can be particularly difficult.

### How this aim could be achieved:

- Improve needs based access to age appropriate services
- Streamline and simplify eligibility criteria and processes for services
- Ensure service providers, people with an ASD, their families and carers have easy access to current, reliable information and research
- Consolidate and improve existing resources to provide trustworthy information about ASDs and available supports.



### What is currently available?

The Victorian Government is taking steps to simplify access to services. For example:

- **DEECD's review of the eligibility criteria for the ASD category of the PSD** recommended systemic reform, including early intervention and professional development, which will be addressed through regional strategic plans.
- The **DHS regional Intake and Response Service** provides information about supports and services for people with a disability and their families, including those with ASD.
- A range of **community service organisations**, including Autism Victoria, the Association for Children with a Disability and Carers Victoria, receive funding to provide information services.
- The **Disability Online website** <[www.disability.vic.gov.au](http://www.disability.vic.gov.au)> provides information on service options.
- The **Office of the Senior Practitioner**, DHS Disability Services, is working to improve the quality of life of young people with an ASD who are at risk of being or are subject to restrictive interventions. Assistance to access additional service supports is also provided to families.
- **DEECD regional Early Childhood Intervention Services (ECIS) Central Intake Service** provides service information for young children with a disability and their families, including ASD.
- DEECD has developed **practice guidelines for ECIS intake** to support consistent practice and timely access to intervention.
- **Information about service options** for young children with a disability and their families is also available at [www.ecis.vic.gov.au](http://www.ecis.vic.gov.au)
- Thirteen **Child and Adolescent Mental Health Services (CAMHS)** and a number of University Child Psychiatry services (Monash, Melbourne) conduct assessments for complex presentations of ASD, often with comorbid mental health issues such as anxiety, depression with/without psychotic features and severe behavioural disturbance. CAMHS assesses for ASD, provides early intervention and psycho-education and refers to services for early intervention, respite and support.
- St Vincent's Mental Health and North Western Mental Health jointly auspice the **Victorian Dual Disability Service**, which provides consultation, education and training to specialist clinical mental health services in relation to people with both intellectual disability and mental illness.
- **Mental Health and Drugs Division**, DHS is overseeing a project to reduce the waiting list for complex ASD assessments in CAMHS and to assist CAMHS increase efficiencies in assessment and maintain a sustainable response to service demand.

**Commonwealth initiatives** aim to better support families with children with an ASD, via the Helping Children with Autism Package. DEECD and DHS are working with the Commonwealth Government to ensure initiatives complement state programs.



## B. Strengthen the ASD expertise of the workforce

**Aim:** That all professionals and workers are well educated about ASD, are compassionate, culturally aware and are able to offer the best service to people with an ASD, their families and carers.

### Why is this a priority?

People with an ASD, their family and carers will have contact with many workers and professionals over the course of time. Families and carers report that generally the professionals they come into contact with are poorly informed about ASD and are ill equipped to offer them the best service. The story from other countries is consistent with these comments.

From identifying early signs and affirming the family's concerns to offering compassionate and appropriate service at home, school or in an employment context, workers are a key resource for people with an ASD, their family and carers.

Professionals and workers offering direct services and supports need to be knowledgeable about ASD and relevant evidence based interventions. Workers who may have less direct contact, for example, transport staff or housing officers, also need to be well informed about ASD and able to offer compassionate service.

There are five elements to strengthening the workforce:

1. Undergraduate, postgraduate and in-service ASD training of professionals and workers.
2. Developing good systems and processes, including accreditation of training bodies and programs/models.
3. Support for service providers in their therapeutic, information giving and referral roles through opportunities for secondary consultation and mentoring.
4. Involvement of people with an ASD, their families and carers in the development of training and in-service material.
5. Development of specific ASD awareness programs for key workers in other areas, such as GPs, police and the justice system.

### How this aim could be achieved:

- Implement a cross-sector workforce development strategy that includes training, secondary consultation and mentoring.
- Ensure that training organisations providing ASD education and training are accredited.



### What is currently available?

Fulfilling DEECD's vision of an inclusive education experience for all students will require equipping school staff with the knowledge to enable them to support children with an ASD. This will involve raising awareness of the disability in schools and across the wider community.

Current work in this area includes:

- **Western Autistic School (WAS)** provides professional development through the Autism Teaching Institute. In an Australian first, the Institute delivers nationally accredited autism specific training courses for teachers at the Vocational Graduate Diploma level. Scholarships have been provided for teachers to enrol in this Graduate Diploma course,
- **Regional Autism Consultation and Training networks (ReACTs)** have been set up through the Autism Consultation and Training NOW (ACTNOW) Strategy to identify and respond to autism specific training and consultation needs in a local area. As a result, early childhood professionals have opportunities for workforce training, ASD skills development and secondary consultation.
- DEECD has introduced **workforce initiatives** for ECIS, including incentives for graduates to work in ECIS, for ECIS staff to work in rural areas, and scholarships for ECIS staff to undertake further study.
- Alongside State Government programs, the **Commonwealth's Helping Children with Autism initiative** includes professional development to strengthen the ASD skills of educational staff.
- **DHS Disability Services** accesses training for accommodation, behaviour intervention and case management staff.
- The **Office of the Senior Practitioner** provides training, workshops and consultation to disability support workers and families about support strategies to reduce behaviours of concern.
- Recently a component called 'Supporting Individuals with Autism Spectrum Disorder' has been included in the **Disability Certification IV training**.

### C. Extend and link key services and supports especially at times of transition

**Aim:** To ensure good communication and collaboration between different parts of the service system, especially during times of transition, so that good quality services are coordinated and delivered smoothly.

#### Why is this a priority?

The service system is complex and can be confusing for individuals and families seeking assistance.

The signs of an ASD may not be clearly discernible, which can make a diagnosis difficult. There may be co-existing problems, such as an intellectual disability or a mental health condition, which may call for extra assessments or tests. Often there are waiting lists for service and access to information can vary.



Many people with an ASD and their families will have contact with general service providers, such as GPs, who may not have specialty knowledge of ASDs, so identification and referral can be delayed. Individuals and families can feel isolated and confused with little information as they are referred on, wait for services or pay for assessments that may not provide a definitive diagnosis. Uncertainty about a diagnosis can be made worse by a lack of information and blocks in the service system which prevent individuals and families from getting the services they are advised they need.

People with an ASD, their families and carers report that there is no apparent organised pathway of service from identification of a problem to diagnosis, intervention and support. Part of the problem has been identified as lack of workforce education about ASD, but there are other factors as well. Insufficient linking up of services and professionals involved in the care and support of people with an ASD, their families and carers, and limited sharing of information means that there are delays and gaps and that the same story has to be retold many times. These system and process problems make transitions from one part of the service sector to another, for example from kindergarten to school, very difficult.

People with an ASD require planned and targeted support prior to and during times of transition at all life stages. Parents and professionals report that many people with an ASD experience significant stress when their routines are changed or their accustomed care, education or work arrangements are modified or disrupted.

Transitions from one type of service to another often coincide with life stage changes, for example from adolescent to adult services. The stress and anxiety associated with the transition to different services or professionals can be made worse if sensitive management and additional support based on the needs of the person with an ASD are not available.

Service support during times of transition has been identified as critical, which highlights the need for good links between services.

People with an ASD, their families and carers have a valuable role in appraising the services they use and providing feedback. Service planning could benefit from their contribution.

#### How this aim could be achieved:

- Extend available services to meet demand for key services (including diagnostic services, behaviour support, social skills programs, respite and early intervention)
- Better coordinate services, clarify referral pathways and strengthen communication between service providers
- Ensure that services work with people with an ASD, families, and other providers to plan for and support transitions
- Develop and support regional networks to consolidate a locus of expertise and experience
- Develop culturally aware, whole family approaches to service delivery
- Ensure that transition planning approaches are holistic and include the whole family and that the planning process is formalised and proactive
- Strengthen the role of the state autism peak body in providing information and support to people with an ASD, families and community support groups
- Build on adolescent, parent and sibling support programs



- Work with families and people with an ASD to make sure information resources meet their needs
- Build on parent education programs
- Create a primary care training program which recognises that Maternal and Child Health Nurses and GPs are a first point of contact for families.

### What is currently available?

- DEECD is supporting the transition for all children, including those with autism, through production of **support kits**, a **common planning template and professional learning materials**. These resources have been developed in partnership with Monash University to assist schools to:
  - improve the transition process for students with ASD who are starting school or transferring to secondary school
  - establish a collegiate support network for teachers of these students
  - facilitate sharing of knowledge, skills and expertise
  - monitor the transition of these students.
- DEECD is introducing a **transition policy** for Victorian children moving from kindergarten to school from 2010. This policy will include Transition plans with information about children's strengths, abilities and learning, a resource kit and professional development.
- DEECD is examining options for **aligning the KISS program and the PSD** to make transition from kindergarten to school easier for children and families.
- ReACTs have developed and implemented a comprehensive **parent training program** and **regional action plans** that target local service gaps, for example, developing service directories, strengthening links with paediatricians and providing ASD information to GPs.
- **Signposts** is a program for all children in the 3–15 year age group who have a developmental delay or intellectual disability. This program assists parents with strategies to prevent difficult behaviour, encourage appropriate behaviour and teach children new skills. Based on the original Signposts program, an ASD module has been developed for families with a child with an ASD.
- The Commonwealth Helping Children with Autism Package will support the development of an **Autism Early Learning and Care Centre** at La Trobe University Children's Centre. The Victorian Government has committed \$500,000 to this project and is working with the Commonwealth Government. The Helping Children with Autism Package will also support the development of playgroups for young children with an ASD or with ASD-like symptoms, and will provide up to \$12,000 funding to families over two years for children between 4–6 years of age with a diagnosis of ASD. In addition, the Parenting Research Centre will provide web-based information for families and face-to-face information and support sessions in partnership with ECIS. New Medical Benefits Scheme (MBS) items have been introduced for paediatrician diagnosis of an ASD and for allied health involvement in the intervention care plan.
- **Managed Individual Pathway (MIP) plans** are provided to students 15 years and over in government schools.



MIP plans aim to help young people to:

- make a smooth transition from compulsory schooling to further education, training and employment
- develop skills to manage their pathways throughout their working lives
- develop their knowledge, understanding and experience of opportunities in education, training and employment.

Additional support is provided to students at risk of disengaging or not making a successful transition to further education, training or secure employment.

Students participating in youth pathways programs in TAFE institutes or Adult and Community Education institutions also have pathways plans.

- The Futures for Young Adults program is available to eligible students from completion of schooling until age 21. The types of options that can be supported on the Futures Program include:
  - trying employment either independently or through local employment programs
  - getting involved in community-based activities or training
  - Undertaking further study independently at TAFE or university.

## D. Provide appropriate educational opportunities

**Aim: That people with an ASD have the best chance to realise their educational potential:**

### Why is this a priority?

Formal education can help students achieve their goals and fulfil their potential. Apart from equipping students with academic skills, the educational process provides a social function as children and young people have an opportunity to learn how to mix with their peers, understand boundaries and social rules, and respect the knowledge and authority of teachers and others. Education prepares students for full participation in society as adults.

To get the most out of their schooling, students with an ASD need assistance. Teachers may also need assistance in the classroom or training to ensure that students with an ASD get a high quality educational experience.

Better preparation of teachers, use of appropriate teaching methods and greater support for all students with an ASD are important to ensure that this group of young people are able to benefit from their educational experience.

Making schools 'ASD friendly' will be a good start to ensuring schools are truly inclusive. 'ASD friendly' schools are proactive in their approach to ASD students, are flexible with the curriculum, and employ appropriate teaching strategies. 'ASD friendly' schools provide a safe place for students with an ASD where they receive respectful treatment. 'ASD friendly' schools are inclusive of parents in planning for the student, provide support on a needs basis and aim to ensure that the whole school community is more aware of the needs and strengths of the person with an ASD.



### How this aim could be achieved:

- Provide support to students with an ASD, including those with HFA and Asperger's Syndrome.
- Support all schools and educational institutions, including TAFE, to become 'ASD friendly' and responsive to the needs of people with an ASD and their families.
- Increase access points for families eg via satellite centres and baserooms in mainstream schools that will provide a room on site for time out of the main classroom.
- Strengthen the role of those with ASD expertise to offer innovative options and support in special and mainstream, government and non-government educational settings.
- Support the tertiary and vocational education sectors to offer autism inclusive programs, and to support the individual's transition into a work or day placement opportunity.
- Make opportunities available for lifelong learning and/or engagement for people with an ASD.

### What is currently available?

The Victorian Government is committed to ensure that all students with an ASD have access to facilities to enable them to participate fully in educational programs.

Current work in this area includes:

- The State Government is providing **additional ECIS and KISS packages** during 2008–12.
- The **PSD** assists students in government schools to maximise their educational potential. Students with ASD can be supported in different school settings including integration into a mainstream school, enrolment in a special school and enrolment in a school for students with ASD.
- Work is underway to improve service delivery for students with a disability and enhance their educational outcomes. This includes:
  - development of the **0–8 learning framework**
  - development of an **Abilities Index model of support**.
- DEECD is responding to the diverse learning needs of all students by **raising awareness** amongst all teachers and providing specialist support for teachers working directly with students who have an ASD.
- A review of **Student Support Services**, undertaken in 2008, recommends that Student Support Services Officers have a key role in providing expertise in the development of support plans for students with disabilities to ensure their ongoing educational development.
- DEECD is investigating **options for specialist provision** that build on what works. Outreach models, base rooms attached to specialist schools and support rooms in regular schools could provide greater choice for families and accommodate diversity of need.



- **Day Programs, Futures for Young Adults and Individualised Support Packages** can support a variety of educational opportunities for people with a disability post secondary school in a range of settings.
- The Commonwealth **Helping Children with Autism Package** is providing an opportunity for parents and carers of primary and secondary school aged children with ASD to participate in workshops and information sessions.

## E. Facilitate successful participation in the community

**Aim:** That communities are inclusive and that people with an ASD, their families and carers can participate and make a contribution in their own way through work, recreation or other activity.

### Why is this a priority?

Participation in society is a key tenet of the commitment made to social inclusion by the State Government in *A Fairer Victoria*.<sup>3</sup> People with an ASD have valuable contributions to make to their communities. It is important that they have the best chance to make a contribution and take advantage of opportunities and benefits that come with participation.

Research shows that outcomes for people with an ASD in adulthood are not as good as they could be.<sup>4</sup> Many young adults with an ASD make valuable contributions to their families and to people around them. However, making a contribution is very hard without support.

The lack of public understanding and awareness of ASD can make it difficult for people with an ASD, their families and carers to participate in ordinary social activities, such as sporting and leisure activities. Getting a job and keeping it is another challenge for those able to work. Sometimes there is assistance with getting a job, but not enough help to retain it. Employers and co-workers often don't understand.

Barriers to participation also exist for the families who are the carers of a person with an ASD and who report lack of tolerance, isolation, restraints on the capacity to work and decreased income, which in itself can reduce participation.

Increasing the participation of all Victorians in their local communities is important; it strengthens community cohesiveness and can have a positive impact on the wellbeing of people with an ASD, their families and carers.

### How this aim could be achieved:

- Implement an ASD public awareness campaign
- Introduce a peer awareness campaign in schools
- Develop targeted information for particular service provider groups, leisure/sporting activity providers and mainstream health professionals

<sup>3</sup> Department of Premier and Cabinet (2005). *A Fairer Victoria. Creating opportunity and addressing disadvantage*. Department of Premier and Cabinet, Melbourne.

<sup>4</sup> Howlin, P., Goode, S., Hutton, J. & Rutter, M. (2004). Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry*, p45.



- Strengthen accommodation and support models to better meet the needs of people with an ASD
- Work with leisure and recreation providers to ensure access to these community resources for young people, adults and ageing people with an ASD
- Work with the Commonwealth Government to ensure that employment support programs better meet the needs of those with an ASD
- Ensure a range of age-appropriate social support programs are available for people with an ASD, their families and carers.

### What is currently available?

- **Early Childhood Intervention Service Flexible Support Packages (ECIS FSP)** support children with a disability or developmental delay, including children with ASD, from birth to school entry, their families and carers. ECIS FSP provides additional services and supports not usually available through universal or ECIS services. Services are tailored to meet the individual needs of the child and to support the family to optimise the child's development and ability to participate in family and community life.
- **Specialist Children's Services teams** and about 60 **community service organisations providing ECIS** work with families to identify their priorities and put in place strategies to support the participation of children and families in everyday activities in their local community.
- **Access for All Abilities** is a Victorian Government initiative coordinated by Sport and Recreation Victoria that supports a more inclusive sport and recreation sector through publications, such as the Good Play Space Guide, and professional development opportunities.
- **Career Start** assists recent graduates with a disability to gain employment in the public and community sectors. The program aims to assist 200 graduates during 2007–11. Funding is allocated via grants to employment service providers, community organisations and education and training organisations.
- **New Workforce Partnerships (NWP)** link disadvantaged jobseekers to employers with skills and labour shortages, with a focus on jobseekers who are clients of State Government community support services, including people with a disability or mental illness. These funds are now fully committed to 29 projects that will assist more than 560 people into ongoing work across Victoria.
- **Youth Employment Scheme (YES)** provides apprenticeship and traineeship opportunities within the Victorian Government for disadvantaged young people aged 15–24. YES is providing 450–550 positions during 2008–09.
- Other supports to assist people with a disability to participate in the community, including people with an ASD, their families and carers, include advocacy services and community building initiatives (for example, MetroAccess and RuralAccess, Deaf access, disability inclusion workers).
- Commonwealth programs that assist people with disabilities, including ASD, to enter the workforce, include:
  - Commonwealth Disability Employment Network, Job Network and Job Access
  - National Mental Health and Disability Employment Strategy.



## F. Develop a robust evidence base about ASD

**Aim:** That Victoria develops a systematic approach to the collection of information about ASD and participates in any national initiative to ensure consistency across the country.

**Aim:** That research into ASD is encouraged, especially in fields where there is little evidence-based knowledge.

### Why is this a priority?

Current knowledge about the development of ASDs, pathways to service, unmet demand for service, and the outcomes of interventions for people with an ASD is limited. Comprehensive data collection will increase knowledge and assist with decision making. The availability of accurate data and evidence is crucial to the development of any service system. In an environment of limited resources and competing agendas, data can significantly influence funding decisions.

Increased ASD research and the development of an evidence base about effective interventions is critical. When available, evidence should be easily accessible to people with an ASD, their families and carers and widely distributed to professionals and service providers to inform practice and future service planning. The collection of data on the prevalence and incidence of ASD is important in understanding the increase in the prevalence of ASD and the factors driving this increase.

### How this aim could be achieved:

- Develop robust ASD data systems to inform service planning and projections
- Ensure Victoria is involved in data collection initiatives at a national level
- Develop a research agenda to guide investment in ASD research, prioritising areas where little evidence is currently available
- Extend the evidence base about effective interventions, educational outcomes and service delivery models through targeted evaluation of services and research
- Ensure service providers, people with an ASD, their families and carers have easy access to current, reliable information about research findings.

### What is currently available?

DEECD has developed **practice guidelines** for ECIS intake workers to support consistent practice and timely access to intervention.

- The Office for Government Schools conducts **ongoing analysis and monitoring** of student numbers for those students supported under the ASD category of the PSD.
- The Office of the Senior Practitioner, Disability Services, DHS, has developed easy to read and **evidence based information** handouts for families about ASD and adolescence, focusing on pubertal transition, increased behaviours of concern and sexuality issues.
- The ACTNOW Strategy continues to develop research based **fact sheets for professionals** to support their work with children with an ASD, their families and carers.

I go to a youth group in Geelong each fortnight called Winning Days.

There are 2 girls and 4 other boys = 7 in total.

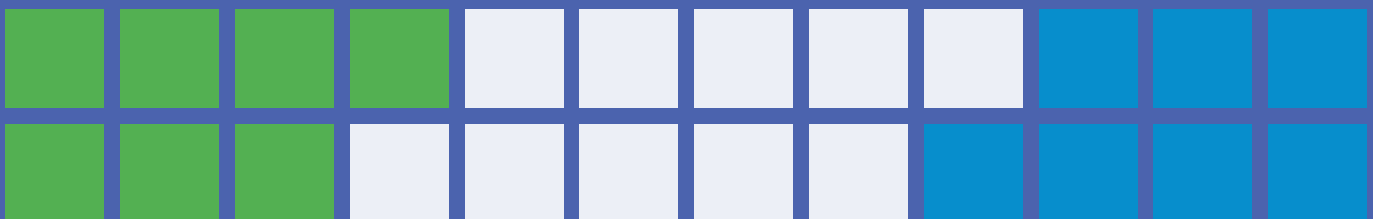
I consider these kids to be good friends. We go to lots of places and do lots of activities such as golf, bowling, yugioh, music festival, the go carts, the Werribee zoo, etc.

Lots of the kids either don't go to school (home schooled) or only go part time.

The ones at school don't have many friends and it is hard when you're at home to meet kids our own age so it's great to go and mix and have fun with kids our own age.

I like these kids. They are kind and I feel really safe around them. The group laughs a lot. We have a Shrek doll that we play catch with and it's a laugh.

Adolescent with Asperger's Syndrome





# Implementing the Plan

## Accountability for implementing the Plan

Diagram 1 presents the main components of the governance arrangements for implementation of the Autism State Plan, which are a lead minister, the Minister for Community Services, an Inter-Departmental Committee (IDC) and a Stakeholder Advisory Group supported by the nominated lead department. These arrangements ensure cross government involvement and provide stakeholders with an active role.

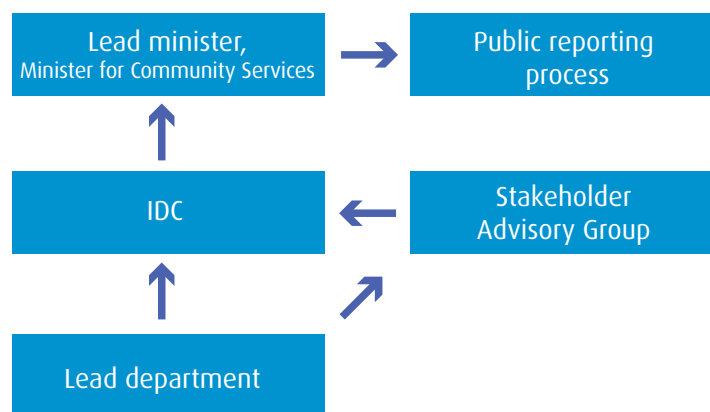


Diagram 1 Components of the governance model for implementation of the Plan

### Governance components, roles and responsibilities

The IDC will oversee the implementation of the priority actions identified in the Action Schedule (Table 1) and the development of strategies for implementation in the medium to longer term.

The Stakeholder Advisory Group will provide advice and inform the IDC about matters directly related to the implementation of the Plan.

## Implementation over the longer term

The six priority areas will guide work over the next 10 years. The following section provides information about current government supports and the context for new investment and program activity identified under Priority Actions in the Action Schedule.

Victorian Government departments, with the advice of the Stakeholder Advisory Group, will continue focused effort over the life of the Plan with the goal of better meeting the needs of people with an ASD, their families and carers, across the lifespan. In the coming years, future investment in the Plan will be guided by this input and be considered alongside other initiatives as part of usual government budget processes.



## Commencing Implementation – Action Schedule

The Action Schedule provides information about new activity and expansion of current activity for people with an ASD, their families and carers planned for commencement in 2009-10. As a context for this new work, information about current, ongoing service activity is also included.

In the first and second columns, the Priority Areas and the corresponding aims are listed. In the third column, a sample of current work is noted under each priority, and in the fourth column, information about new or expanded activity planned for commencement in 2009-10 is presented.

The funding that has been provided in the 2009-10 budget, (listed in the far right hand column of the Schedule), 'kick-starts' implementation and builds on current services and supports. There have also been 2009-10 budget investments in other government program areas that provide services and supports to people with an ASD, including Disability Services and the Department of Education and Early Childhood Development.

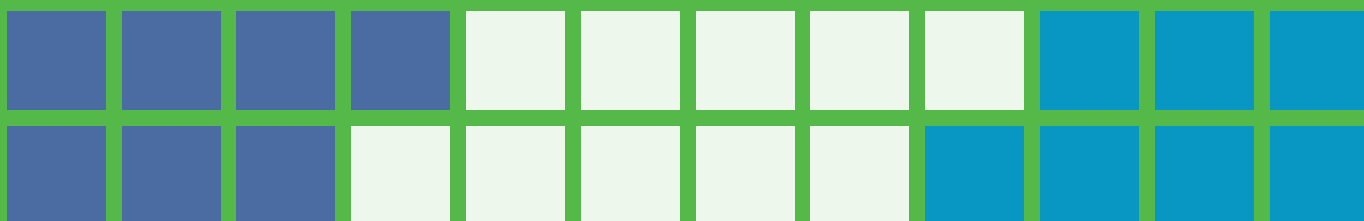
### 2009-2019

The Plan has a 10 year timeframe, with the new work signalling the beginning of the implementation period. Much of the new work will be ongoing, while some is intended to solve a specific short-term problem and is time limited, for example, the Child and Adolescent Mental Health Wait Reduction project.

## I am

I am friendly and kind  
I wonder why some trees form seeds  
I hear someone talking in my head  
I see the swing moving by itself  
I want a little kitten  
I am friendly and kind  
I pretend to find a friend  
I feel shivery and cold  
I touch the mostly friendly animal in the world  
I worry about mum in danger  
I cry when something is taken away from me  
I am friendly and kind  
I understand Australian mammals  
I say people should not be cruel to animals  
I dream that the world is free from mean people  
I hope for a better world  
I am friendly and kind.

12 year old boy with Autism





Priority	Aim	Foundations – Current Work
<p><b>Making it easier to get support</b></p>	<p>That all people with an ASD, their families and carers have ready access to the advice and support they need.</p>	<ul style="list-style-type: none"> <li>• Diagnostic assessments for complex presentations of ASD across Victoria for children and young people</li> <li>• ASD diagnostic assessment for adults can form part of a comprehensive psychiatric assessment</li> <li>• Early Childhood Intervention Service intake provides initial information and referral</li> <li>• Review of the eligibility criteria for the ASD category of DEECD’s Program for Students with Disabilities</li> <li>• Information regarding specialist and general disability supports and services and service options available</li> </ul>
<p><b>Strengthen the ASD expertise of the workforce.</b></p>	<p>That all professionals and workers are well educated about ASD, are compassionate, culturally aware and are able to offer the best service to people with an ASD, their families and carers.</p>	<ul style="list-style-type: none"> <li>• Consultation, education and training for specialist clinical mental health services by Victorian Dual Disability Service</li> <li>• Autism Consultation and Training Strategy (ACT NOW) – ASD educational resources via website, parent training program, Regional Autism Consultation and Training networks (ReACTs) of professionals which identify and respond to local training needs</li> <li>• Maintain and resource the Autism Teaching Institute based at Western Autistic School</li> <li>• Autism Teaching Institute training courses for teachers and DEECD scholarships for teachers</li> <li>• Disability Certification IV training includes a component called ‘Supporting individuals with ASD’</li> <li>• Additional training for DHS disability staff on a needs basis</li> <li>• The Workforce Strategy: Improving supports for people with a disability 2008-2013 has been developed as one of a number of initiatives to further build the capacity of the industry, in particular the workforce, to respond to the changing support needs of people with a disability.</li> </ul>
<p><b>Extend and link key services and supports especially during transition</b></p>	<p>To ensure good communication and collaboration between different parts of the service system, especially during times of transition, so that good quality services are coordinated and delivered smoothly.</p>	<ul style="list-style-type: none"> <li>• Support transition of all children including those with ASD from prep to school and in schools</li> <li>• 500 additional Early Childhood Intervention Services places and 50 Kindergarten Inclusion Packages during 2008–2009 for all children with a disability or developmental delay, including those with ASD</li> <li>• Early Childhood Intervention Services flexible support packages to support children with a disability, tailored to meet individual needs</li> <li>• Disability services, including case management, respite services, behaviour intervention support, therapy services and individualised support packages</li> </ul>



Commencing Implementation – Priority Actions 2009-10	Investment to support implementation
<ul style="list-style-type: none"> <li>• Implement Child and Adolescent Mental Health Services Wait List Reduction Project and increase sustainability of Child and Adolescent Mental Health Services (CAMHS) ASD diagnostic services</li> <li>• In collaboration with the Commonwealth Government, participate in the establishment of the Autism Specific Early Learning and Care Centre</li> <li>• Improve access to information about where to get help for people with an ASD and their families</li> <li>• Introduce a standard developmental assessment tool and a secondary screening tool into Maternal and Child Health Services</li> <li>• Simplify eligibility criteria for ASD category of the Program for Students with a Disability</li> <li>• Take joint approach with Commonwealth Government re Helping Children with Autism initiative and State Government services</li> <li>• Implement enhanced regional planning, introduce a common approach to assessment and develop a new data collection to inform planning and monitoring for children and young people with disabilities or a developmental delay, including those with ASD. Over the four years this initiative will also deliver a new early childhood intervention quality assurance framework, program standards, and a comprehensive workforce strategy.</li> </ul>	<p>\$512,000 in 2009</p> <p>\$500,000 in 2009</p> <p>\$250,000 over 2 years (a)</p> <p>Prior funding commitment</p> <p>Prior funding commitment</p> <p>Current activity</p> <p>\$9.0 million over four years</p>
<ul style="list-style-type: none"> <li>• Further develop the Regional Autism Consultation and Training networks (ReACTs)</li> <li>• ASD education and training to specialist clinical mental health services and others e.g. DEECD's Specialist Student Support Officers</li> <li>• Autism Secondary Consultation and Training Strategy (ACT NOW): Strengthen the ASD skills of the specialist early childhood workforce by providing secondary consultation and mentoring</li> <li>• Develop an ASD training package for disability case managers</li> <li>• Develop regional leadership and secondary consultation services for disability case managers working with families and people with an ASD</li> <li>• Develop an ASD training package for disability accommodation staff</li> <li>• Scholarships for education staff to undertake vocational post graduate studies in autism</li> <li>• Develop a targeted early childhood intervention workforce plan</li> <li>• Encourage Commonwealth involvement in the ReACTs</li> <li>• Implementation of the Victoria Police Mental Health Strategy (April 2007) includes the review and update of police training in recognising and responding to people with mental health and disability issues in a variety of operational contexts. This will necessarily apply to interactions with victims, witnesses, offenders and people in need of assistance who have ASD</li> </ul>	<p>\$678,000 over 4 years</p> <p>\$209,000, over 4 years</p> <p>\$598,000 over 4 years</p> <p>\$200,000 in 2009</p> <p>\$900,000 in 2009</p> <p>\$400,000 in 2009</p> <p>\$2.287 million over 4 years</p> <p>Prior funding commitment</p> <p>Current activity</p> <p>Current activity</p>
<ul style="list-style-type: none"> <li>• Expand the capacity of specialist mental health services by appointing new dedicated coordinators to manage assessment and treatment</li> <li>• Increase individual support packages for people with a disability, including people with ASD</li> <li>• In 2009, develop an online Managed Individual Pathways resource for parents of students with disabilities regarding pathways to employment</li> <li>• 500 Early Childhood Intervention Services places and 25 Kindergarten Inclusion Packages during 2009–2010 for all children with a disability or developmental delay, including those with ASD</li> <li>• Roll out kindergarten to school transition kit across the state to support all children, including those with ASD</li> <li>• Improved access to peer, parent and carer support groups</li> <li>• Disability Reform Program of Day Services to support more individualised, flexible approaches for people with disabilities including those with an ASD</li> <li>• Implement two child and youth mental health service redesign demonstration projects over four years, through a coalition of providers, to plan and deliver a more integrated and comprehensive mental health care for children and young people 0-25 years. This will include a stronger focus on early identification and intervention of a broader range of mental health problems including ASD.</li> <li>• Youth mental health dedicated response across a broad range of conditions with outreach capacity for young people up to 25, including for those with an ASD</li> <li>• Youth justice mental health initiative to provide clinical treatment and care coordination to young people involved with youth justice services</li> </ul>	<p>\$3.727 million over 4 years</p> <p>\$29.95 million over 4 years(c)</p> <p>Prior funding commitment</p> <p>Prior funding commitment</p> <p>Included in (b) below</p> <p>Included in (a) above</p> <p>\$12.48 million over 4 years</p> <p>Prior funding commitment 2008-2012</p> <p>\$13.8 million over 4 years</p> <p>\$3 million over 4 years</p>



Priority	Aim	Foundations – Current Work
<p><b>Enhance and provide appropriate educational opportunities</b></p>	<p>That people with an ASD have the best chance to realise their educational potential.</p>	<ul style="list-style-type: none"> <li>• Support for students with ASD in mainstream, special or ASD specific schools via the Program for Students with a Disability</li> <li>• Maintain and resource the specialist ASD schools</li> <li>• Augment support services to assist government schools support students with disabilities</li> <li>• Signposts program to optimise the young student’s learning, behaviour and potential</li> <li>• Students 15 years and over in government schools are provided with individual pathway plans and support as a means to continued education, training or full-time employment. Additional support is provided to students at risk of disengaging or not making a successful transition</li> <li>• Futures for Young Adults program provides support during school transitions including to further education</li> <li>• Students participating in youth pathways programs in TAFE institutes or Adult and Community Education institutions also have pathways plans</li> <li>• Disability Day Programs and Individualised Support Packages provide support for a variety of educational opportunities</li> </ul>
<p><b>Facilitate successful participation in the community</b></p>	<p>That communities are inclusive and that people with an ASD, their families and carers can participate and make a contribution in their own way through work, recreation or other activity.</p>	<ul style="list-style-type: none"> <li>• Access for All Abilities – providing sustainable sport and recreation opportunities for people with a disability throughout Victoria</li> <li>• Career Start provides assistance to recent graduates with a disability to gain employment in the public and community sectors</li> <li>• New Workforce Partnerships links disadvantaged jobseekers, including those with disabilities, to employers with skills and labour shortages</li> <li>• Youth Employment Scheme provides apprenticeship and traineeship opportunities within the Victorian Government for young people 15-24 years</li> <li>• Disability Action Plans assist organisations to develop inclusive policies and practices. Public sector organisations are required to develop a Disability Action Plan under the Disability Act 2006</li> <li>• Advocacy services, community building initiatives e.g. MetroAccess and RuralAccess to help local communities be more inclusive</li> <li>• Early Childhood Intervention Services flexible support packages to support children with a disability, tailored to meet the individual needs assists the child and family to participate more fully in community.</li> <li>• Individualised supports to assist people with a disability participate in community life</li> </ul>
<p><b>Develop a robust ASD evidence base</b></p>	<p>That Victoria develops a systematic approach to collection of information about ASD and participates in any national initiative to ensure consistency across the country.</p> <p>That research into ASD is encouraged, especially in fields where there is little evidence based knowledge.</p>	<ul style="list-style-type: none"> <li>• Development of Early Childhood Intervention Services intake guidelines to support consistent practice and timely access to intervention.</li> <li>• Ongoing analysis of numbers of students supported under the ASD category of the Program for Students with a Disability</li> </ul>



Commencing Implementation – Priority Actions 2009-10	Investment to support implementation
<ul style="list-style-type: none"> <li>• Reform DEECD's service and support to students with an ASD via 5 year regional ASD plans. The plans will enable schools to respond to the needs of students with an ASD at the following levels:               <ul style="list-style-type: none"> <li>– Support Level One: A Whole-School Approach to Building a Positive School Culture</li> <li>– Support Level Two: A Targeted Approach to Identify and Address Need</li> <li>– Support Level Three: An Intensive Response to Address Need</li> </ul>               This support model applies to the education of all children with an ASD, including those not receiving funding under the Program for Students with Disabilities, and those with High Functioning Autism and Asperger's Syndrome.             </li> <li>• Implement Disability Education Awareness Campaign to reduce discrimination and improve attainment rates of students with disabilities</li> <li>• CAMHS in Schools Early Action teams in partnership with schools, to identify and treat children with behavioural problems in primary school years</li> </ul>	<p>\$550,000, 2009-10</p> <p>Prior funding commitment</p> <p>\$4.2 million over 4 years</p>
<ul style="list-style-type: none"> <li>• Broaden community awareness of ASD</li> <li>• Further develop the Transition to Employment Program for people with a disability including those with an ASD</li> <li>• Individualised supports to assist people with a disability to participate in community life</li> </ul>	<p>Current activity</p> <p>\$16.69 million over 4 years</p> <p>Included in (c) above</p>
<ul style="list-style-type: none"> <li>• Development of ASD diagnostic guidelines for Mental Health diagnostic staff</li> <li>• Contract out ASD research projects to inform future policy by evaluating existing models of support, or trial and evaluate new models of support for people with ASD.</li> <li>• Development of standardised assessment tools and evidence based practice via CAMHS Wait List Reduction Project</li> </ul>	<p>\$225,000 over 4 years</p> <p>\$1 million in 2009</p> <p>Included in (d) above</p>

