



Autism State Plan

Consultation paper



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What is autism? What is an ASD?

There are a number of definitions or descriptions of autism. Some define it as a mental illness and others as a neurological or neurodevelopmental difference that is classified as a developmental disability.

There is general agreement that autism is one of a group of 'Pervasive Developmental Disorders'. Although not officially defined in any international medical classification code, the term 'Autism Spectrum Disorder' (ASD) is commonly used to encompass Autistic Disorder, Asperger's Syndrome, and Pervasive Developmental Disorder – Not Otherwise Specified, which is 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.

Although the cause of autism/ASD is unknown, it can be identified from early childhood onwards and affects a person throughout their whole life. Autism/ASD is described according to a spectrum with varying degrees of pervasive impairment that range from mild to severe. Although individuals with these disorders exhibit qualitative impairment in social interaction, restricted repetitive and stereotyped patterns of behaviour, interests and activities, and qualitative impairment in communication, they can also present measurable and admirable differences in perception, attention, memory and intelligence.



Background

Over the past 20 years there has been more and more research undertaken about Autism Spectrum Disorder (ASD) in Australia and overseas. This has helped to improve our understanding of ASD and the effect it has on individuals, their families and the community. People with an ASD may need many kinds of assistance. To provide the best possible support and improve the lives of people with an ASD, more work is needed that involves people with an ASD and their families.

In Australia and across the world, more people are being diagnosed with an ASD and there is a greater focus on the needs of people of all ages with an ASD. Health, education and training and employment systems and services can play an important role in helping people with an ASD.

Governments in Australia and elsewhere are interested in joining up and improving services so that people with an ASD and their families and carers can find and get the services and supports they need, when and where they need them. Governments also want to learn more about programs and services that achieve positive results for people with an ASD. A major goal is to help people with an ASD and their families find their way around the services that are available and get the ongoing support they need as well as support during key stages of life, such as moving into and out of school and work.

The Victorian Government is developing an Autism State Plan in partnership with Autism Victoria. This will be the first time an Australian government has developed a plan that specifically considers the needs of people of all ages with an ASD.

To develop this plan, the government will:

- look at the current demand for services
- evaluate the findings of the *Autism Secondary Consultation and Training Strategy*¹ (ACTNOW)
- identify gaps in services
- develop strategies to make services more effective.

The Autism State Plan will be developed by the Department of Human Services, the Department of Education and Early Childhood Development, and Autism Victoria. These partners, with input from the Department of Premier and Cabinet, prepared this consultation paper.

To make sure that the Autism State Plan reflects the views and experiences of people with an ASD, their families and carers, people and organisations that provide services, doctors, teachers and academics and others, there will be a consultation process.

This consultation process will include:

- A consultation paper – people can read the paper and provide written feedback.
- Meetings will be held across Victoria to give people an opportunity to talk with government and Autism Victoria representatives about the Autism State Plan.

After the consultation, key directions will be identified.

A second stage of consultation will be undertaken during 2008 before the draft Autism State Plan is submitted for government consideration later in 2008.

In the meantime, to find out about what is happening with the plan, you can check the websites of the Department of Human Services autismstateplan.dhs.vic.gov.au and Autism Victoria www.autismvictoria.org.au/policy.

Principles to guide the Autism State Plan

When developing the Autism State Plan, the partners involved will be guided by some basic principles that will ensure that the Plan reflects the Government's social policy commitment to create a *Fairer Victoria*. These principles are:

- Autism Spectrum Disorders are **lifelong** conditions. People with these conditions may need a variety of supports throughout their life.
- **Respect** for the individual and their family/carers and their knowledge, contribution and relationships is paramount.
- 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.
- **Disadvantaged** individuals with an ASD and their families will be a **priority** for support.
- Support should encourage people with an ASD and their families and carers to **speak up, say what they want and make their own decisions**.
- Support should be based on **sound evidence**.

¹ From March 2004 through 30 June 2007 funding was allocated to Monash University, Centre for Developmental Psychiatry and Psychology by the Department of Human Services to develop and implement the *Autism Secondary Consultation and Training Strategy*. The focus of the initiative was the provision of training, information and resources, community development and secondary consultation to support staff delivering services for children with an ASD aged from birth, prior to school entry, and their families. In May 2007 the Minister for Children announced the extension of funding for another 18 months until the end of 2008.



About this consultation paper

The consultation paper has two sections:

Part A has seven sections that each deal with a key topic. These topics have been chosen because research shows us that they are important in improving outcomes for people with ASD. Under each topic there are key issues and some possible actions to address those issues.

Part B takes a more detailed look at the key topics presented in Part A.

Have your say

Accompanying this consultation paper is a Response form.

Individuals, families and service providers are invited to write down and send us their views and responses to this consultation paper. We are interested to know if you agree that the issues we have identified are major issues for people with an ASD and their families and what you think of the actions we have proposed. You can also use the Response form to tell us about other important issues.

When you have filled in the Response form, you can send it to:

Jennifer Phan, Department of Human Services
Level 20, 50 Lonsdale Street, Melbourne Victoria 3000.

If you prefer, you can fill in an electronic version of the Response form which you will find at:

autismstateplan.dhs.vic.gov.au

Download the electronic version and when completed, you can send it to the email address below:

autismstateplan@dhs.vic.gov.au

If you have any questions about how to provide your comments, send an email to:

autismstateplan@dhs.vic.gov.au

or phone 03 9096 0526

Case stories

The Autism State Plan is an opportunity to celebrate the achievements of people with an ASD and the contribution they make to society. We invite you to provide your own story or a story about a person or family you know through work, school or socialising.

If you want to provide a case story, please go to the Autism Victoria website to download the Case Story Template at:

www.autismvictoria.org.au/policy/

You can either return the case story to the email address below:

admin@autismvictoria.org.au

or send it to:

PO Box 235, Ashburton Victoria 3147.

Closing date for your response

The final date for submission of your Response form is:

Monday 3 December 2007.

Thank you for your interest in contributing to the development of the Autism State Plan.

The Autism State Plan Working Group

September 2007

A note on informal supports and caring

The Department of Human Services recognises the important role that carers play in supporting people with an ASD. In 2006, the Department of Human Services published a policy document – *Recognising and supporting care relationships*² – which acknowledges the important role of relationships between people giving and receiving support and care. This policy document is relevant to families and others who care for a person with an ASD.

When we think about support and caring we often think about services provided either publicly or privately, like schools, child care, health services, support agencies and so on. Yet these ‘formal’ services are only one part of the equation. Informal care and support that comes from families, individuals and communities (including school and sporting clubs, faith-based groups and others) is really the foundation of care and support in our society. ‘Carers’ can be parents, husbands and wives, brothers and sisters, adult children, friends and community members. Each caring relationship is different. The issues, needs and challenges faced by people can depend on their health, their age, their culture, their network of support and their access to services.

Care relationships and support needs change over time. Those who care for a person with an ASD often have lifelong caring responsibilities. They often worry about the future when they may be less able to be a carer.

The *Recognising and supporting care relationships* policy outlines three overarching principles – recognition and respect, support, and participation – these are the most important elements of supporting care relationships. As for other carers, we should support those who care for people with an ASD, recognise and respect their knowledge and contribution, and involve them as partners in decision making.

This consultation paper has been prepared with the knowledge that the many families with a person with an ASD take on a significant caring and support role. The value and the costs of this role are recognised. Support for carers will be examined in the development of the draft Autism State Plan.

² Material from the *Recognising and supporting care relationships policy framework 2006* and the *Disability services carer action plan 2006* has been used in the preparation of this section.



Part A – Key issues

Section 1: Information and support for individuals and families

Research shows that people cope best, are less stressed and more healthy when they have some control over their lives. Coming to terms with a diagnosis of an ASD can be very stressful. To help individuals and families cope, it is important to help them get the information they want, when they want it. Information can help people understand and feel that they have some control. This can help improve their wellbeing.

In recent times, the stresses of caring for others have been more broadly acknowledged. Caring can have a negative effect on family life and on relationships. This can be made worse if more than one family member has an ASD. Families also often talk about the financial stress and the concern about the future.

What are the issues?

Issues relating to information and support include:

- Services assisting families are not consistent in the information they provide and when they provide it.
- It is not clear who is responsible for talking with families about their concerns and for providing information. Some service providers have little knowledge about the resources available and other services that people can use.
- People are not sure about how reliable information is. While they may get information from the Internet, this may not be the right information. They are also not sure where to go for reliable information and guidance.
- There is a lack of support for families in their role as carers, they don't get enough relief and other family members can be affected as everyone is focusing on the person with the ASD.
- The costs of looking after someone with an ASD mount up and can cause extra stress.
- Little is known about what it is like for people in other family or community groups, for example, Indigenous people and those who don't speak English.
- Families can become isolated because they find it difficult to manage the behaviour of a person with an ASD in public.
- The broader community doesn't understand ASD and the types of behaviours it can cause. If they don't understand, it is difficult for them to accept the differences.

What can we do about it?

1. Provide training for workers to improve their knowledge of ASD and how to respond to the information needs of people with an ASD and their families.
2. Develop information resources about options and supports that are available to help people at different life stages.
3. Find out the information and support needs of Indigenous people, those who come from a different cultural or language background and young people and adults with an ASD. Find out how these needs could be supported.
4. Develop a strategy to increase public understanding and awareness of ASD.

What do you think?

Have we identified the major issues related to information and support needs of people with an ASD and their families?

Can you suggest other actions that could be taken?

Please fill in the Response form with your comments.



Section 2: Finding services – the pathway

When we talk about ‘service pathways’ we mean working with professional services. This can start when a person first seeks advice and continue through to being referred for diagnosis and working with services to provide treatment and support.

The experience of being involved with services can be described as the ‘service journey’. The journey can cover the various stages in a person’s life – from childhood to adolescence to adulthood and old age. This journey may include starting kindergarten, going to school, going on to secondary school and further education or getting a job.

A service pathway should map out the services and options for an individual and family. People with an ASD and their families use a wide range of services that may be provided by government (public) and by private services. Some of these services will be specialist services, catering specifically to the needs of people with an ASD. Some will be universal services that are available to everyone, like maternal and child health services or government schools. Others will be general services, like community health services and hospitals.

What are the issues?

Issues identified by families and others include:

- The service system is very confusing and that it can be difficult to get the services that are recommended.
- Sometimes there is no clear ‘path’ of where to go. Other times, there may be a clear path, but services have long waiting lists or are too expensive.
- Families and individuals often have to tell their stories over and over to different services. It would help if service providers worked together more often.
- Some people don’t know that they can get help.
- At major life stages, such as leaving secondary school, it can be difficult to find services for the next stage.
- Often the professionals don’t seem to know as much about ASD as you would expect and this limits how much they can help.

What can we do about it?

Here are some suggestions for actions that could make it easier for you to get the services you need:

1. Clearly identify ways to access services and make the pathway to services simple.
2. Produce resources that help people find the services they need.
3. Strengthen supports for individuals with an ASD and their families at all key times of change across their lives.
4. Better educate the workforce about how to help families get the services and supports they need, in particular disadvantaged sections of the community such as Indigenous people or those who don’t speak English.

What do you think?

Have we identified the main problems about finding the way to the services you need?

Can you suggest other actions that could be taken?

Please fill in the Response form with your comments.

Section 3: Accessing services

Getting the service you need depends on a number of factors, such as:

- whether there is a service
- being able to get to a service
- being able to afford a service
- meeting the eligibility criteria.

Apart from universal services, such as maternal and child health and schools, many public services are aimed at particular populations or sections of the population. Most services have requirements, or criteria, that people need to meet before they can use the service. These may relate to their age, gender, culture, where they live, or their specific condition.

What are the issues?

Issues identified by families and others include:

- In some areas ASD is recognised as a disability, but in others, including Victoria, it is not. Many people believe that this is not fair because it stops people with an ASD who do not have an intellectual disability from receiving some specialist services, such as Department of Human Services Disability Services and Department of Education and Early Childhood Development Program for Students with a Disability.
- Having to prove eligibility for services over and over is an unnecessary burden.
- Even when a person is assessed as eligible for a service, there may be a long wait before receiving services because other people have priority.
- While it can be easier to meet the eligibility criteria of private services, the cost and location may make them difficult to use.

What can we do about it?

1. Develop one set of eligibility criteria for people with an ASD for services in the public sector, so they don't have to prove that they are eligible over and over.
2. Develop an up-to-date resource that tells people about the eligibility criteria and what they have to do to meet the requirements.
3. Develop better ways to manage demand so people don't have to wait so long for services.
4. Help people with an ASD who do not have an intellectual disability to make sure that they have every chance of reaching their full potential.

What do you think?

Have we identified the major problems involved in getting the services people need?

Can you suggest other actions that could be taken?

Please fill in the Response form with your comments.



Section 4: Diagnosis of ASD

Diagnosing an ASD can be complex and take time. There is no simple 'diagnostic test'. Also, because ASD affects communication, interaction and behaviour, multiple observations and examinations by a team of specialist professionals are needed before a diagnosis can be made.

It may be the parents, maternal and child health nurse, GP or kindergarten/child care staff who first raise a concern about a young child's development. A referral to a GP and then to a paediatrician is made. At the same time, a referral to early childhood intervention services is recommended to ensure that the child and family are linked into services and support as early as possible. Usually, the GP or the paediatrician will make a referral for diagnostic assessment. Child and adolescent mental health services offer multidisciplinary assessment for the most complex cases and to assist in clarifying diagnosis. A limited number of other services – some in the private sector, some in the public sector – offer ASD diagnostic services.

For older children, signs may be identified by school staff who will report their concerns to the family and, where appropriate, make referrals through the school support services for assessment. More commonly for adolescents and adults, ASD is identified when an individual presents to other services or is referred for assessment because of anxiety or depressive problems.

What are the issues?

Issues identified by families and others include:

- Parents may express a concern but the professionals may not identify a problem – it's as if they're not listening or else say it's best to 'wait and see'.
- Workers who are in contact with children and young people often miss or don't know the signs of ASD.
- There is little support during the diagnostic process including while waiting or once a diagnosis is made.
- Waits for diagnosis are too long.
- Assessments that are required to meet eligibility requirements for services are not part of the diagnosis process.
- There are relatively few services or private practices that conduct diagnostic assessments for ASD, which can make it hard for families especially in rural areas.

What can we do about it?

1. Conduct training for workers who are in contact with people with an ASD to improve identification and to increase the number of professionals who can participate in diagnosis.
2. Develop good practice clinical guidelines for ASD diagnostic assessment.
3. Strengthen diagnostic services so they can operate in accordance with good practice principles.
4. Improve communication between workers to reduce the number of times individuals and families have to repeat their stories.

What do you think?

Have we identified the major issues associated with diagnosis of ASD?

Can you suggest other actions that could be taken?

Please fill in the Response form with your comments.

Section 5: Adolescents and adults with an ASD

Adolescence is a period of significant change for all young people. For some young people with an ASD, they improve during adolescence and can achieve a great deal. For others, adolescence can be a time of greater difficulties, including increased anxiety. It can be during adolescence that Asperger's Syndrome is first diagnosed as a young person develops anxiety or depression.

Making the move from school to work requires early planning and support. It is also helpful if the people who will be working with the young person with an ASD are also prepared and understand. Lack of understanding and knowledge about ASD can be a major barrier to young people as they try to move on to work.

Some people with an ASD continue to improve as they become adults. However, most people with an ASD will need some support throughout their lives. Not a lot is known about the issues for ageing adults with an ASD, but families worry about their child's long-term financial security, housing and care.

What are the issues?

Issues identified by families and others include:

- There is a lack of support during times of change, such as when leaving school or looking for work.
- It can be very stressful caring for a person with an ASD who does not become independent.
- Often people who work in schools, employers and co-workers, and service providers do not understand the behavioural, communication and social difficulties of the person with an ASD. This can create a barrier to studying, finding a job and a place to live.
- Families and parent carers have significant and ongoing concerns for their child with an ASD. They may be concerned about their child's behaviour and also worried that other people will take advantage of them. They may also be concerned about who is going to care for their child in the future.

What can we do about it?

1. In schools where young people and adults with ASD are studying, make sure that staff are trained and that the organisation is able to support them and help them learn.
2. Develop information resources about available transitional support at points of change throughout life.
3. Develop a model with employment agencies and employers that provides a way for employers to support people with an ASD.
4. Look at housing options for those people with an ASD who may need minimal support to gain independence.

What do you think?

Have we identified the major issues related to the adolescent and adult years?

Can you suggest other actions that could be taken?

Please fill in the Response form with your comments.



Section 6: Workforce

People with an ASD and their families and carers will come into contact with people who work in health, welfare, education and housing. This contact may be occasional or ongoing.

Other people will also work with people with an ASD from time to time, including police, custodial staff, aged care staff, housing officers, alcohol and drug services staff and accommodation staff.

Research from many parts of the world shows that not all people who work with people with an ASD are experts on ASD. In fact, many people who work in services such as government schools, hospitals, community health centres and police stations have little knowledge or understanding of ASD.

There is a need for training of professionals and workers. Both the Department of Human Services and the Department of Education and Early Childhood Development are funding training programs. This work is a beginning. There are still many sections of the workforce that do not have access to training.

What are the issues?

Issues identified by families and others include:

- While there are many terrific service providers, there are also many who have little knowledge and few skills in the area of ASD, even highly trained people like doctors and teachers. This is a concern because it limits the guidance and support that these people can offer.
- Many workers caring for or working with young children lack knowledge and skills, which limits their ability to identify signs of ASD.
- Service options are limited for people with an ASD and their families because there are not enough professionals trained in assessing and helping people with an ASD.
- Some families say that they know more about ASD and how to manage it than the workers they are dealing with.

What can we do about it?

1. Work with professional organisations to promote training of their members, including paediatricians, psychologists and psychiatrists.
2. Make sure that training and information is suitable for people who work with Indigenous communities and with people from different cultures and who don't speak English.
3. Continue a secondary consultation service (like ACTNOW) and expand it.
4. Ensure that experienced staff help new staff who are working with people with an ASD.

What do you think?

Have we identified the major issues related to the workers who come in contact with people with an ASD and their families?

Can you suggest other actions that could be taken?

Please fill in the Response form with your comments.

Section 7: ASD data

Having accurate information, or data, is important if we are to improve services for people with an ASD and their families.

By collecting data, we get a better understanding of services – who needs them, who uses them and how they help people with an ASD.

Accurate data might also help to explain why more people are now identified as having an ASD than before.

Collecting data can improve the way we plan and deliver services.

What are the issues?

- Data is important for planning. It seems that there is not a lot of information available about how people come to use services or about those people who don't use services.
- Sometimes data is available but it doesn't provide information about ASD because this is not the first or main condition that the person is diagnosed with.
- Information may not be collected about certain groups of people, such as Indigenous people, people from different cultures, people who don't speak English, and older people.
- Sometimes data can't be used because it is inaccurate or not consistent with other information collected, for example, a different definition of ASD being used to collect information.

What can we do about it?

1. Victoria should participate in a national approach to ASD data collection.
2. Look at other ways to collect information about ASD.
3. Make ASD a reportable condition – that means requiring certain workers, such as doctors, to report ASD to a central source.
4. Redevelop existing data systems so that people with an ASD who use services can be identified.

What do you think?

Have we identified the major issues related to ASD data?

Can you suggest other actions that could be taken?

Please fill in the Response form with your comments.



Part B – Detailed discussion

Section 1: Information and support for families and individuals

Types of information

Information is important to help people understand and cope with an ASD. There are different types of information. Ideally, the right information should be provided or available at the right time, in the right place. It should also be in the right language, and form for the user.

Table 1 below provides a sample of some of the questions that families and individuals may ask. These sample questions show that people have different information needs.

Table 1: Different types of questions, different information needs

What	<p>What is an ASD?</p> <p>What does the diagnosis mean? For me, for our family?</p> <p>What will happen next? In the future?</p> <p>What work will I (my child) be able to do?</p>
Where	<p>Where do I go for a diagnosis?</p> <p>Where do I (my child) go for help?</p> <p>Where can I (my child) go for therapy?</p> <p>Where will I (my child) live when older?</p>
Who	<p>Who can help?</p> <p>Who are the experts?</p> <p>Who can I talk to?</p>
Which	<p>Which service can I go to?</p> <p>Which school will cater for my child's needs?</p> <p>Which TAFE or university?</p>
How	<p>How do I find out what I need to know, when I need to know it?</p> <p>How do I know what services will help?</p> <p>How do I know if the information or service is reputable?</p> <p>How do I get the service that is needed?</p> <p>How much will it cost?</p>

Information needs are different, depending on the person and their family.

People may be ready for information at different times. They may also prefer to receive information in different ways, for example some people like to have information they can take away to read; others want to be told about it; others want to find out for themselves.

Service providers and people involved in the support and care of people with an ASD are important sources of information. They have a role in providing information and showing people how and where to find information.

What happens now?

Families often receive information from service providers.

There are many pamphlets, fact sheets, websites and resource kits for families and individuals. Some families want to read everything, while others feel overwhelmed by lots of information.

Key organisations, such as Autism Victoria, provide information by phone, a website and printed material (Autism Victoria Infoline). Through ACTNOW, a website has been developed (<http://www.med.monash.edu.au/spppm/research/devpsych/actnow>) that provides up-to-date, information for families, individuals and professionals. Other useful sites, such as www.autismhelp.info, provide tips on ways to assist children with an ASD.

Service providers also link families to support groups, schools and playgroups. Getting information from others in similar situations can be very helpful.

Families want the people working with them to be honest and to give them good quality information and advice about how to get the services and support they need. While service providers put a lot of effort into providing information to families, there are areas for improvement. Information could be more consistent and be given to them at the right time. Many parents say that the best source of information about support services comes from other parents.

Often families may get information about services or support, but they find it difficult to get the services that are recommended. They need information and support to find and access services.



Adolescents and adults

Little is known about the information and support needs of young people and adults and their families. The Internet is reported to be a popular way for some young people with an ASD to get information and to link up with others.

This consultation process provides an opportunity for people to tell us about the information needs of young people and adults with an ASD.

Quality

Individuals, families and service providers are concerned about the quality of the information that is available, particularly the information available from the Internet.

The Internet is a terrific resource for people who have access to it and are comfortable using it. However, it can be hard to tell if the information is reliable. Service providers report that families can be misled by claims of special treatments that promise a cure.

The websites of university centres or autism organisations are a good place to start.

Section 2: Finding services – the pathway

Why do we talk about service pathways?

Being able to find and access the recommended services usually results in better outcomes for people with an ASD and their families and carers.

A service pathway is like a map of relevant services that also gives people information about the services – such as what they are, who can use them, how much they cost, and how you enter or access the service.

Having a clear service pathway and knowing when and how to access services is important because if an ASD is identified correctly and early, this can help people get the right services at the right time. It can also help reduce the negative impact an ASD can have on the person, their siblings, parents and carers.

What happens now?

Identifying which services are available at any point in time for any person or family is not always straightforward because individual situations vary and location and cost of services vary.

People with an ASD and their families often use both formal and informal services and supports. Formal services are public and private services that work with people with an ASD and their families. Informal services include support groups, Internet chat rooms and local community groups and resources.

Individuals and families can find the service journey confusing and hard to find their way around. Most often, people with an ASD move forwards and backwards along the service pathway, between different parts of the service system. The service pathway for people with an ASD is shown in Figure 1 on page 23.

The person and their family may also choose to use private services to supplement or replace public services. Therefore, the service journey can be quite different for each person.

Unlike conditions that are identified at birth or soon after, ASD is not usually identified until early childhood and in some cases in adolescence or adulthood. A child diagnosed with an ASD before the age of six years will have to meet eligibility criteria to receive a range of government services, from Early Childhood Intervention Services (ECIS) and Carer's Payments through to support at school via the Program for Students with a Disability.

People whose ASD is not identified until they are older may have used different services, including mental health and justice services, before a diagnosis is made and the right support is found. Sometimes an ASD may co-exist with another condition, for example a mental illness or an intellectual disability. If this other condition is identified before the ASD, the person may have accessed different services again.

If a person has an ASD and an intellectual disability, they can usually access a range of disability services. For those people who have an ASD but do not have an intellectual disability, access to specialist services is limited (as is shown in Figure 1 on page 23). This can be a major problem for some families because the person with an ASD can be very disabled by the condition, even though they are not eligible for disability services.

The Department of Education and Early Childhood Development has a Program for Students with Disabilities. This program provides extra resources to government schools to help them deliver education for students who have a moderate to severe ASD without an intellectual disability, as well as to students with ASD who are intellectually disabled. To be eligible for this program, a multidisciplinary team consisting of a psychologist, speech pathologist and a child psychiatrist or paediatrician, must diagnose students with an ASD. Diagnosis may take some time, and the professionals involved may not know what information is required by the department to establish eligibility. This can cause delays in students receiving the best possible support.

The service system continues to change rapidly and there are significant differences between metropolitan and regional and rural service systems. Assistance is often needed to help families find and access services. A designated key worker or case manager can help and is available through some programs.



Key transition points

The key transition points for students are usually: entry to kindergarten, transition to primary school, transition from primary to secondary school, transition from autism-specific schools or special schools to mainstream school settings and vice versa, and transition to post-schooling and further education.

Support for people with ASD at these transition points is a high priority. While there are some good transition programs, often support is limited. Getting the right services at these transition times can be difficult.

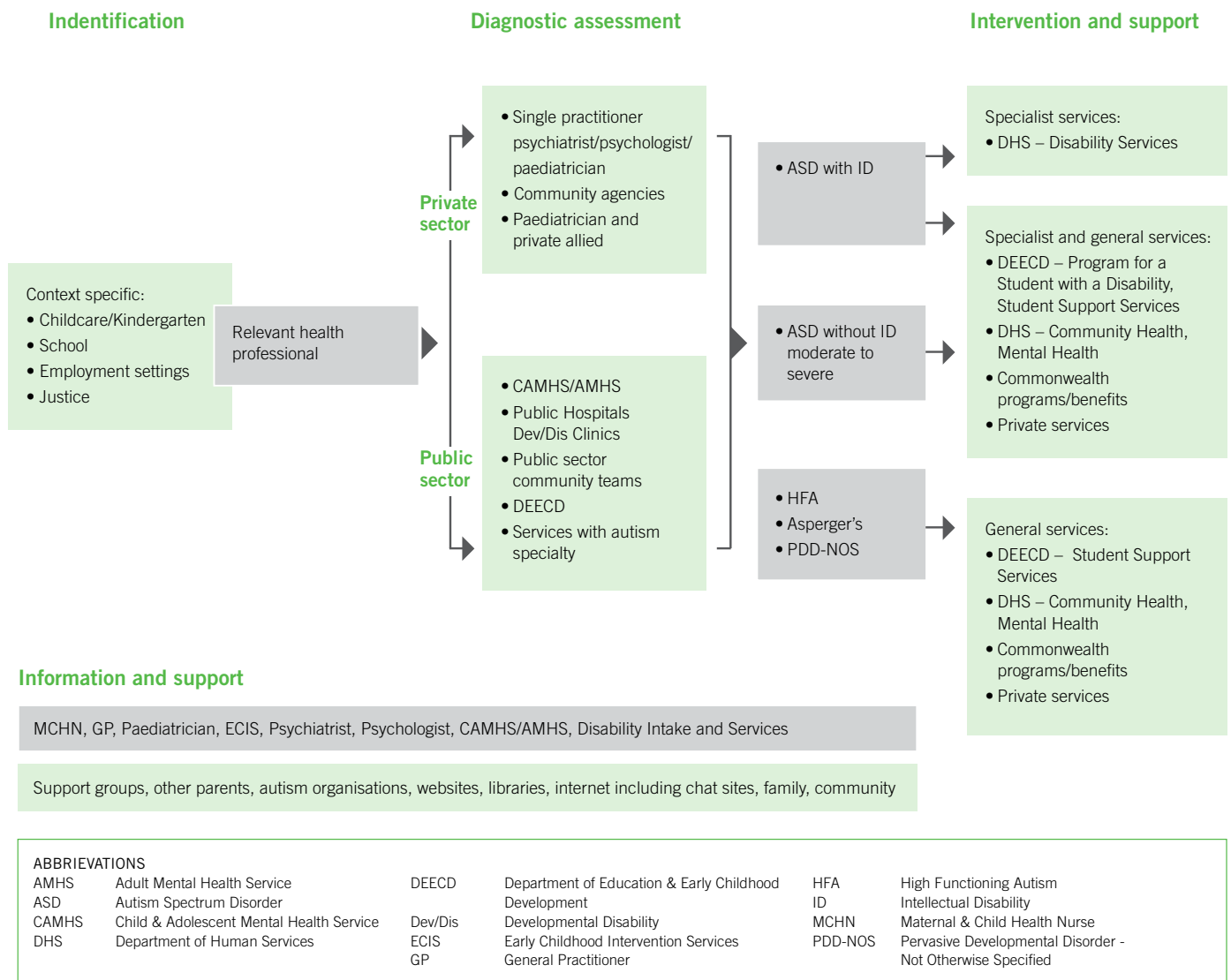
At the same time as trying to find services, people are also trying to adapt to change which can be very stressful for the person with an ASD and their family. Parents often say that moving from a supportive ECIS environment to school, where they have less contact with the school and fewer supports, is difficult.

People with an ASD who do not have an intellectual disability

People with an ASD who do not have an intellectual disability can access general services. However, often the staff of these services do not have the necessary skills to work with people with an ASD. Because of this, people without an intellectual disability may not have their needs fully met in general services.

As many people with ASD who do not have an intellectual disability need support with daily living skills, it is important to assess their abilities to make sure that services are right for them.

Figure 1: Four service components of the service pathway





Section 3: Accessing services

Research shows that the sooner a person gets support, the better.

Getting that support is not always easy. Because many people want to access public services, there are often strict rules about who can use the service and sometimes long waiting lists.

Private services may be easier to get into, however they can also be expensive and may not be where you need them.

Families say that there are no clear service pathways and this makes it difficult for them to find the best services for the person with an ASD. The situation is made even more difficult by eligibility and availability issues.

Department of Education and Early Childhood Development

The Program for Students with Disabilities provides extra resources to government schools to help them provide education for eligible students. Eligibility criteria for the Program for Students with Disabilities are developed from World Health Organisation definitions of disability, and are designed to identify students with severe or profound disabilities.

A review of the eligibility criteria for support under the category of Autism Spectrum Disorders is being undertaken and will be implemented for funding in the 2009 school year.

Students supported by the Program for Students with Disabilities and other students with learning needs are encouraged to join in Student Support Groups which work with the student and their parent or guardian to develop short and long term learning goals.

Schools also receive resources through their Student Resource Package to develop and deliver teaching and learning programs for all students. Support services, including psychologists, social workers, youth workers, speech pathologists, visiting teachers and curriculum consultants, are available to assist all Victorian Government schools.

Department of Human Services

The Department of Human Services funds and provides a range of services, including universal, general and specialist services in the areas of disability services, child and family services, juvenile justice, health, mental health, welfare and housing. All these service areas may be relevant to people with an ASD and their families, depending on the family situation and preferences.

What are the issues?

The Department of Education and Early Childhood Development and the Department of Human Services specialist services are targeted to specific groups and have precise eligibility criteria. Some families and service providers are unhappy with present eligibility criteria, such as eligibility for Disability Services and the Program for Students with a Disability.

The Program for Students with a Disability is designed to support students with more severe or profound disabilities. It is generally not available to people with ASD who are described as 'high-functioning'. All students with additional needs have access to Student Support Groups, the Language Support Program and Student Support Services Officers, including psychologists, social workers, youth workers and speech pathologists, and autism-specific schools provide outreach to mainstream schools.

In Victoria, ASD is not recognised as a disability. Many families say that this is unfair because people with an ASD who do not have an intellectual disability can have behavioural, communication and social problems that stop them from becoming independent and participating in society.

Others say that it makes sense to invest in this 'high-functioning' group to help them live independently, contribute to society and be less dependent on public services.

Some argue that a range of services should be available to meet the complex needs of the person with an ASD and their family. Some community service organisations offer a range of services that are joined up to offer continuity as well as a way to develop knowledge in ASD.

ASDs are conditions that can affect multiple members of a family. Whether or not the affected members have an intellectual disability, the whole family situation needs to be considered.

Section 4: Diagnosis of ASD

Steps in the diagnostic process

For ASD, as for other conditions, getting a diagnosis usually consists of four steps: identification, referral for diagnosis, diagnostic assessment and recommendations for treatment and support.

This process may occur step by step. But this is not always the case. Occasionally, an individual and family may go through different parts of the process before a diagnosis of an ASD is made. Often with young children, treatment and support start before a diagnosis is made.

Figure 2 below sets out the steps in the diagnosis of ASD.

Sometimes delays can occur in diagnosis. This may be because the early signs are not picked up or a wrong referral is made. It may be because there are long waiting lists and there are not many people qualified to do diagnostic assessments. People living in the country may find it hard to access a service for diagnosis. The cost of a private diagnosis may be too expensive.

Good diagnostic practice

Having a correct diagnosis is so important. It means you can seek the right treatment, information and support. Throughout Victoria there are examples of good diagnostic practice and services that strive to meet the needs of their local community.

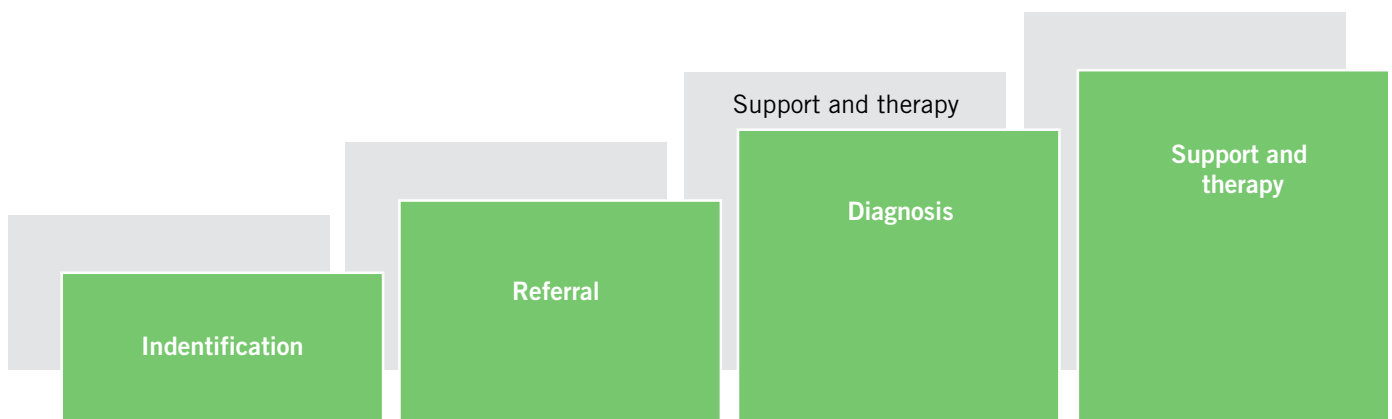
In some areas, there is little or no wait for diagnosis; in other areas the wait is long, but people waiting may be offered an initial assessment to make sure they are linked to supports. Some services also provide a service after diagnosis to help individuals and families understand the diagnosis and take the next step.

Studies in other countries like New Zealand, England and the United States of America have shown that the best diagnostic process is made up of the following parts:

1. **Prompt referral for early intervention** and family support for young children.

Where a developmental delay or other problem has been identified, linking the individual with an ASD and family into available supports in the local community is important. This may include support groups, local council programs, and information about Commonwealth benefits. Having a full review by a paediatrician is an early first step once a concern has been raised.

Figure 2: Steps towards diagnosis and therapy with delay points flagged





2. **Pre-diagnostic screening consultation:** A screening consultation can be valuable because it ensures those on the waiting list for diagnosis are waiting for the right service, and provides an opportunity for the individual and family to ask questions, be reassured about the process and to be linked or referred to services and supports.
If a wait for diagnosis is lengthy, the person who conducts the screening can be a contact point for the individual/family and referring professionals.
3. Fulfilling the **information needs** of the individual/family.
Families report that they often need to go over the information that is supplied by professionals, especially at the time of identification and diagnosis. Follow-up contact is important – either by members of the diagnostic team or other professionals involved in the ongoing care plan.
4. **Multidisciplinary team:** A number of different types of professionals make a team and work together to assess an individual and to agree on a diagnosis. This approach is recognised throughout the world as the best way to diagnose an ASD.
The multidisciplinary team is usually made up of a paediatrician, a psychologist and a speech therapist. Other professionals who can be involved are occupational therapists and psychiatrists. Child and Adolescent Mental Health Services may also be involved where the case is complex and to assist in clarifying other problems or conditions.
For adolescents and adults, a psychiatrist, a psychologist and an educational therapist are usually involved in diagnosis.
After the diagnosis is made, the multidisciplinary team develops a plan about what therapy and support is needed.
5. **Timely diagnosis:** The aim is to provide support and intervention for an individual/family and a diagnosis within a reasonable period from the time of first referral.
6. **Good communication** can ensure continuity of care between the various professionals and agencies involved and with the individual/family.
It is important that the diagnostic team has access to previous assessments and reports done by other professionals and can refer on appropriately.
They should also provide detailed yet sensitive feedback to families.
Key professionals involved in the ongoing care of a child or young person, such as a maternal and child health nurse, GP or paediatrician, need to be kept 'in the loop' about the diagnosis and the plan to support the child and family.
7. **Comprehensive intervention support plan:** For each individual, the effects of ASD are different, which means that the intervention plan needs to be designed for them. Recommendations from each member of the diagnostic team are included to inform the intervention plan. Where Child and Adolescent Mental Health Services have been involved in clarifying the diagnosis, their recommendations about treatment for other problems and disorders should also be included. The intervention plan needs to contain clear goals and strategies for each setting, relevant to the individual.
8. **Post-diagnosis support** with links into services and supports that have ongoing involvement.
Families report that the time after diagnosis can be difficult as they need support and opportunities to go over the diagnosis, what it means and how it will affect their family and the future of their child. Continuity between the diagnosing team and others involved in the care and support of the individual/family is very important at this time.

Section 5: Adolescents and adults with an ASD

Adolescence

Adolescence can be a difficult time for anyone. It is a time when people want to fit in and belong. For a person with an ASD it can be even more difficult to be accepted by others and they can become anxious and depressed. It can also be a difficult time for families who have to deal with a person who is physically larger, who may have an intellectual disability and whose behaviour may be challenging. It is a time when families can reach breaking point as stress mounts.

Adolescence happens at the same time as young people are moving from primary to secondary school. It is important that schools are able to provide support and protection for students with an ASD, while also helping them to maximise their potential by working with their strengths.

Better understanding of ASD throughout the school community and training of staff will help develop a safe and supportive learning environment for adolescents with an ASD.

Young adults and adulthood

People with an ASD prefer routine and predictability. As an adolescent becomes an adult, there are many changes. Planning for the move from secondary school to further learning or work is very important because it can affect the ability of the person with an ASD to learn, work and live more independently.

Adults with an ASD have said that the right support during adolescence can make a difference to what they can achieve as adults.

Many young adults with an ASD do not become fully independent. They mature slowly and sometimes others' expectations of them are too high.

The move into adulthood has been identified as a time when support can break down. Having limited options for study, work, accommodation, leisure and social activities does not help.

Adults with ASD and an intellectual disability may continue to live at home or in supported living settings. They may use a range of disability-funded services, such as supported employment, community participation activities and social recreational programs, as well as mainstream community programs. Many respond well to a structured routine and visual prompts, and an environment that suits their interests and strengths.

Some adults without an intellectual disability find the world of work and social interactions a continuing challenge. Others are able to develop successful careers based on their strengths and learn ways to help them cope with, or minimise, difficulties in dealing with others.

When a young adult with an ASD is not fully independent the family or carer can face major challenges, such as ongoing financial responsibility and the effects of socially challenging or unacceptable behaviour. Young people with an ASD may become involved with police and the justice system because of their behaviour or because they are taken advantage of by others.

Research shows that outcomes for people with an ASD in adulthood are not as good as they could be. Many young adults with an ASD make valuable contributions to their families and to people around them; however, achieving full independence and contributing through work or other activities may be difficult.

Even those with normal or high IQ may not achieve their potential as adults. In fact, the capabilities of those people with an ASD referred to as 'high functioning' may prevent them from getting the support they need to study or work. Adults who are not diagnosed until one of their children is diagnosed with an ASD may have experienced a lifetime of misunderstanding, without the benefit of 'knowing' about their condition or the supports to help them manage it.

Gaps in service, or insufficient support, is a concern because it has been found that support over time is a key factor in the diverse outcomes of the group of people referred to as 'high-functioning'.

Information about the life experiences and the support needs of people with an ASD as they mature into middle and older age is very limited both here and overseas and requires further examination.

What happens now?

Both the Department of Human Services and the Department of Education and Early Childhood Development provide specialist support to eligible adolescents and adults with an ASD. For those who are not eligible for specialist services, support is available in schools through general health and welfare programs and via mainstream Department of Human Services health, welfare and housing services. A summary of some of the specialist and generalist programs available is provided over the page.



Department of Education and Early Childhood Development: Secondary Education

Program for Students with Disabilities

Although there are no secondary schools that cater solely for students with ASD, general specialist secondary schools enrol students with ASD if they also have an intellectual disability. Some autism-specific schools have rooms in secondary colleges, and some provide services for students with ASD in secondary schools. Autism-specific schools offer a range of supports for adolescents with ASD, including weekend social clubs and arts programs for students in mainstream schools.

Year 6-7 reviews are compulsory for most students on the Program for Students with Disabilities. Primary and secondary school staff work together to produce an educational plan for the student's transition into secondary school.

Victorian Government schools establish Student Support Groups for students supported by the Program for Students with Disabilities. All other students with additional learning needs are also encouraged to get involved in the Student Support Groups. The Student Support Group gathers information about the student from their family, records from previous schools and other services. This information is used to develop an understanding of the individual's learning needs and to make recommendations to the principal about the support the person needs and how the budget can be allocated to provide that support. Mainstream secondary schools have Student Welfare Coordinators and access to Student Support Services Officers who can assist with planning and support of students with an ASD.

Managed Individual Pathways (all students)

The Managed Individual Pathways initiative ensures that all students 15 years and over in government schools are provided with individual pathway plans and support to continue education, training or full-time employment.

The Managed Individual Pathways initiative aims to help young people:

- 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 dropping out or not making a transition to further education, training or employment. Students participating in youth pathways programs in TAFE institutes or Adult and Community Education institutions also have pathways plans.

Department of Human Services: Disability Services

Futures for Young Adults provides information, advice and support for up to three years to young people with disabilities who are leaving school. The aim of Futures for Young Adults is to support young people as they make the transition from school to adult life. It also aims to help them to plan ahead, set goals and make informed decisions about their future and the range of options they want to explore after school. To be eligible for Futures for Young Adults support, an individual must meet the eligibility criteria for the Department of Education and Early Childhood Development's Program for Students with Disabilities or equivalent in the Catholic and independent sectors.

Respite and support

Families or carers of adolescents and adults with an ASD who are eligible for Disability Services can access respite support. Respite allows carers to take a short break from caring. Respite support is flexible and can be planned throughout the year so that there are regular or occasional breaks. It is available at short notice or for emergencies. Other forms of support available through Disability Services are:

- Disability Services Supported Accommodation Options (accommodation operated in disability accommodation services and by community services organisations)
- support to live in the community
- daytime activities including Adult Training Support Services
- recreational and holiday programs
- individual support packages, where, based on priority, resources are allocated to a person to provide the support they need.

Specialist services/therapy services

There is a range of services that are focused on the individual and are provided by the Department of Human Services or by community services organisations or private service providers. These services include secondary consultation, assessment, implementing and reviewing specialist treatments, or providing specialised treatment in an intensive live-in facility when behavioural issues and/or involvement with the justice system requires more specific intervention and support.

In summary

Supporting a person with an ASD through life's stages to make the most of their quality of life is a shared goal. The needs of each individual with an ASD differ and the types of support they seek will be different.

Families and individuals manage the challenges of ASD in a variety of ways. Some will seek most of their support through the formal service sector, either public or private, while others will draw on the informal support of friends, family, community or faith-based networks. Many will use both formal and informal support to help meet the needs of all family members.

Various types of support will be needed for life. For some people this will be intense support in a residential setting. Others will continue to live in the family home, and some will manage varying levels of independent living. Other forms of support will be required through adulthood to help a person realise their educational, employment or other life aspirations, including leisure, relationships and stable accommodation.



Section 6: Workforce

The workforce that comes into contact with a person with an ASD, their family and carers is diverse. Workers can be involved at different points and for different lengths of time during the person's life.

While some areas of autism expertise have developed within particular groups of professionals, many workers need education about ASD.

Why is specific training about ASD necessary?

To meet the needs of people with an ASD and their families, a workforce that is educated about ASD and knows how to work with individuals with an ASD and their families, and knows when and where to refer them for support is required.

For example, students with an ASD can be challenging for school staff who may not have had any training or experience with people with an ASD. Although efforts are being made to ensure that specialist expertise is available to schools, they may not have the resources to supervise and support students with an ASD.

Also, improving workforce ASD knowledge and skills, may increase the number and range of service options available to individuals and families because more workers in a greater range of services may be able to provide service.

Identification

Early identification of ASD is very important as it means that the right support can be put in place for the family. Identifying a toddler, child, adolescent or adult with an ASD requires awareness and knowledge. Professionals and workers need to be aware of ASD and able to identify it and refer people to a professional with expert knowledge.

Intervention

Approaches or interventions that work for some groups of people with disabilities may not work for people with an ASD.

Workers who are directly involved in providing therapy for people with an ASD need specialised knowledge. Families and carers are usually responsible for the day-to-day management and care of people with an ASD and they will seek professional advice and support in this role. For professionals to be a resource to families, they need to be well prepared and have had specific ASD education and training.

Support

Professionals and workers need to consider the family as a whole. Families report that sometimes they can become socially isolated because they need to keep to a routine or because the behaviour of the person with ASD makes it difficult for them to be out in public. Workers need to be sensitive to this and to consider the needs of parents, carers, brothers and sisters when planning support.

Outcomes

Not understanding ASD or providing the wrong advice or support can be very negative for the individual and family. A forensic researcher observed that in relation to people with Asperger's Syndrome involved with the justice system:

Failure to correctly identify such persons, or overlooking the features specifically related to their diagnosis, may lead to inappropriate forensic assessment, legal decisions, or clinical interventions⁴.

What happens now?

Training and support

The need for appropriate training of professionals and workers is recognised, and both the Department of Human Services and the Department of Education and Early Childhood Development are funding training programs. This work is a beginning. There are still many sections of the workforce that do not have access to training.

Department of Human Services

Over the last three years, the department, via the Office for Children, has funded a statewide ASD education and training program for early childhood workers. This program is called the *Autism Secondary Consultation Strategy* or 'ACTNOW'. ACTNOW is run by the Centre for Developmental Psychiatry and Psychology at Monash University to provide training, information and resources, community development and a second point of advice to support staff who provide services for children with an ASD aged from birth to school entry, and their families. During the next 18 months, ACTNOW will develop a statewide secondary consultation service to support people working in the field.

Education

For the first time in Australia, the Autism Teaching Institute will deliver nationally accredited ASD teaching courses at the vocational graduate level.

⁴ Murrie, D. C., Warren, J. I., Kristiansson, M. & Dietz, P. (2002) Asperger's Syndrome in Forensic Settings. *International Journal of Forensic Mental Health*, 1, p 69.

Section 7: ASD data

Data collection in Victoria

Available data about ASD in Victoria can be divided into two main types: prevalence studies and administrative data sets.

Prevalence studies

The two key prevalence studies in Victoria are the *Victorian Burden of Disease Study: Mortality and Morbidity (2001)*⁵ and a 2003 ascertainment study, commissioned by the Department of Human Services to estimate the prevalence of ASD in Victorian children aged 0–6 years⁵. The first national prevalence study in Australia was published in 2006⁷. None of these studies consider prevalence in the adult population.

Administrative data collections

People with an ASD use a range of support services, including:

- maternal and child health services
- School Nursing Program
- Early Childhood Intervention Services, including Kindergarten Inclusion Support Services and Preschool Field Officers, Mental Health Services – including Child and Adolescent Mental Health Services and adult mental health services
- Disability Services
- Department of Education and Early Childhood Development, Program for Students with Disabilities
- Aged Care Assessment Program
- Multiple and Complex Needs Initiative
- youth and criminal justice systems
- drug and alcohol services.

While each of these services collect information about the people who use them, they were not designed to collect information about the numbers and experiences of people with specific conditions. Therefore, they cannot accurately identify people with an ASD or provide information about their experiences.

Other issues with the Victorian administrative data sets include:

- These data sets don't collect information about how people come to use services or about people who don't access services.
- Some data sets only provide information about the main condition or primary diagnosis of the client. ASD is often a secondary diagnosis and therefore not included.
- Some data sets collect information about the main condition or primary concern about the client on entry to services and ASD may be diagnosed later.
- Many data sets don't collect information about people with an ASD from groups that may have particular needs, such as Indigenous people or people who do not speak English.
- There is very little information about adults and older people with an ASD.
- Different data collections use different definitions of ASD.
- Sometimes data isn't reported accurately.

Data collection in other states and other countries

In other states of Australia and internationally, governments are investing in data collection about ASD.

In many states in the US and in parts of Europe, governments are setting up autism registers to better collect data about the numbers of people with an ASD. Western Australia is the only Australian State to have such a register.

A recent report commissioned by the Australian Advisory Board on Autism Spectrum Disorders called for an improved national approach to the collection of prevalence data for ASD in Australia.

Next steps

There are opportunities to build on and improve existing data collection to better identify and collect information about people with an ASD using services.

Victoria also has the opportunity to join with and support any moves towards a national approach to data collection about ASD.

⁵ Department of Human Services (2005) *Victorian burden of disease study: Mortality and morbidity in 2001*. Melbourne, Victorian Department of Human Services.

⁶ 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*. Melbourne, Victorian Department of Human Services.

⁷ MacDermott, S., Williams, K., Ridley, G., Glasson, E. & Wray, J. (2006) *The prevalence of autism in Australia. Can it be established from existing data?*, Australian Advisory Board on Autism Spectrum Disorders.

