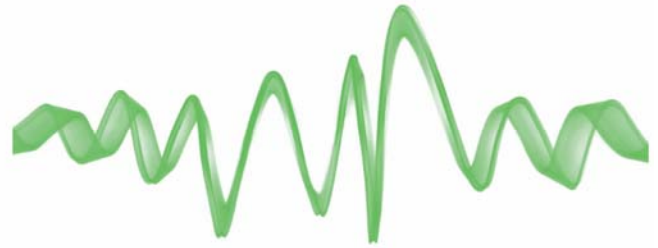


Autism State Plan



Ministerial Foreword

THE HON LISA NEVILLE MP – LEAD MINISTER FOR THE AUTISM STATE PLAN

The development of an Autism State Plan in partnership with Autism Victoria was a Victorian Government election commitment in November 2006. Our shared aim is to build 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 to this process.

I am very pleased to introduce this Summary of Consultation Feedback. Over 720 people participated in 23 consultation forums held across metropolitan and regional Victoria in October and November 2007, and more than 250 provided written comments on the Autism State Plan Consultation Paper released in September. This response demonstrates the importance placed on improving the way we provide support to people with an ASD in our community.

I would like to thank all those people who provided their feedback and in many cases shared their personal stories with the partner organisations (Autism Victoria, the Department of Human Services and the Department of Education and Early Childhood Development). This input by individuals with an ASD and their families and carers, service providers and service organisations, doctors, teachers, academics and others will be crucial to ensuring the Autism State Plan is informed by the wealth of knowledge of those with direct experience of the needs of people with an ASD in our community.

The next step will be for the partner organisations to consider this feedback, follow up suggestions made about innovative service models, and further consider the evidence from Australia and overseas about what things work well or show promise to improve outcomes for people with an ASD. The Victorian Government recognises the diversity of ASD and that this is a whole of life issue. Importantly we need to consider the needs of individuals with an ASD at different life stages and key transition points from early childhood through to adolescence and adulthood.

During the consultation process, many people told us of the need to build a greater community awareness and understanding of ASD. As we approach Autism Awareness Month in May, I hope this Summary will play a role in doing so.

I look forward to considering the draft Autism State Plan from the partner organisations later this year.

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



Autism State Plan Consultation Findings

Background

In the 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 (ASD)'.

Since that time, the government in partnership with Autism Victoria has been working to progress that commitment. A state-wide consultation process has been undertaken to ensure that the Autism State Plan reflects the views and experiences of people with an ASD, their families and carers, service providers, academics, teachers, doctors and others.

Consultation

In September 2007, a Consultation Paper was released to guide consultation with the Victorian community. In total, 252 written submissions from rural and metropolitan Melbourne were received in response. Individuals with an ASD, families and carers, service providers and service or advocacy organisations were all represented in these submissions. The Consultation Paper can be accessed on the Autism State Plan website: autismstateplan.dhs.vic.gov.au

In October and November 2007, a series of 23 forums was held across metropolitan and rural Victoria. More than 720 participants attended. Those involved in the forums included individuals with an ASD, family members and carers, service providers, researchers and others.

There was also the opportunity for people to submit a personal perspective detailing the achievements of a person with an ASD. Thirty personal perspectives were received and selected excerpts will be considered for inclusion in the Plan.

This paper presents an overview of the key outcomes of the consultation process and reflects

on the main themes that emerged from the forums and the written submissions.

The partners developing the Autism State Plan – the Department of Human Services, the Department of Education and Early Childhood Development and Autism Victoria would like to thank everyone who participated in the consultation process by attending a forum or sending in a written submission.

Feedback on overall direction of the Consultation Paper

The State Government has an opportunity through its new State Autism Plan to nurture a remarkable subgroup of citizens within their community, and therefore benefit the entire state rather than consign them to a lifetime of isolation with a perceived disability (Individual with an ASD, written response).

The partners were impressed by the attendance and participation of people across the state at the Consultation Forums and the thoughtfulness of the submissions received. The breadth and depth of knowledge and the ideas that were presented is impressive, and reflects the diversity of experience of the people who participated in the consultation process.

Overall, participants in the consultation process welcomed the State Government's commitment to developing an Autism State Plan and appreciated the opportunity to have input into its development.

The issues and suggested ways forward outlined in the Consultation Paper were emphatically confirmed by those who participated in the consultation process. In general, people were also happy with the Principles outlined in the Consultation Paper. In both the forums and the submissions, other principles and issues were identified and solutions suggested. This feedback is set out in the sections that follow.

What the Partners heard

The challenges of having an ASD for individuals, their families and carers are significant. Those who participated in the consultation said that good services with staff who understand ASD, that are



easy to get and offered at the right time make a big difference. They are sometimes frustrated by not getting the services they need when they need them.

Participants welcomed the focus on ASDs as lifelong conditions and the need for support and therapy to be based on sound evidence.

People who participated in the consultation process were asked about their experiences of good practice and were able to provide examples that we can learn from and build on. Both forum attendees and people providing submissions expressed real appreciation of good service but said that what is needed is more of this good practice rather than isolated examples.

Highlights from the data:

- The majority of those providing written responses indicated that the Consultation Paper had correctly identified the major issues related to ASD.
- Almost all of those who sent in a Consultation Response form provided extra comments and ideas.
- Nearly half of those sending in submissions provided examples of good practice.

Voices of experience: impact of ASD on individuals with an ASD, their families and carers

The ripple effect on the family becomes a TIDAL WAVE! (Family member, written response).

What have we heard from those who know?

Individuals with an ASD spoke of the particular challenges they face on a day to day basis. Family members (and others on their behalf) spoke openly about the stresses of caring for someone with an ASD. Commonly mentioned were social isolation due to behaviours associated with ASD and the lack of community knowledge and understanding,

family stress including negative impacts on siblings, relationship problems, and financial costs associated with accessing specialist therapeutic services, paying for multiple assessments or diagnosis to avoid waiting lists, and travelling to appointments.

Key messages

Individuals with an ASD and their families/carers want good advice, information they can trust and practical support. It's important that quality of life issues for the whole family are considered and that siblings' and carers' needs are not overlooked. Consultation participants said they wanted to feel more confident about what the future might hold for the individual with an ASD whether that be through fulfilling potential and making a contribution to society or through having security about living and support arrangements.

Highlights from the data:

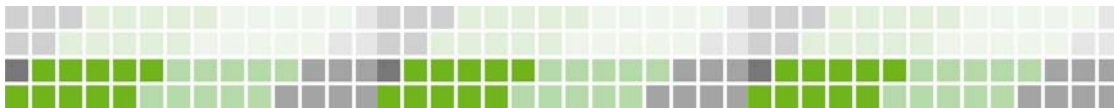
- Approximately two thirds of the people sending in submissions included information about their support needs with ideas about how their situation could be improved.

The distinctiveness and diversity of ASD

ASD is a complex disorder and every person is challenged in a unique way. There are many different therapies available and what works for one does not necessarily work for another (Family member, written response).

What have we heard about the distinctiveness of ASD?

Participants in the consultation process were clear that the State Plan must recognise the diversity of strengths and needs of individuals with an ASD – from those with high functioning ASD or Asperger's to those who have an ASD and a severe intellectual disability or other complex needs. That families may have more than one member affected by an



ASD is another factor that requires a service response that has a family focus.

For many people participating in the consultation, recognising ASD as a disability under the *Disability Act 2006* was key to ensuring that all those on the spectrum (including those with no intellectual disability) had access to service.

Many people talked about the stress associated with the diagnostic process including from before diagnosis to once the diagnosis is confirmed. The particular features of ASD can make diagnosis particularly complex with the result that individuals and families may not have a clear diagnosis for some time or may be given an initial diagnosis which is later revised.

A lack of community understanding of ASDs and the distinctive and diverse nature of these conditions was cited by many participants as causing particular difficulties and concerns for individuals with an ASD, families and carers. A number of people proposed broad community awareness campaigns, and targeted ones for particular groups, be put in place.

Key messages

Not only is there a range in severity of how an ASD might affect a person, but for each person the particular way in which the symptoms manifest can be different. This distinctiveness of ASD can have repercussions for the manner in which services are provided including intervention programs, learning environments, employment and living arrangements.

ASDs are not well understood conditions both within the broader society and within the professional workforce. This creates extra stress for individuals with an ASD and their families and carers who want professionals to listen and to learn from them and involve them in the care and education of the person concerned. Because ASDs are a distinctive range of conditions those who work with people with an ASD need to be flexible and value the strengths of each person.

Service providers also need to understand the particular needs an individual with an ASD may have whether that person has an intellectual

disability or not and provide support where possible. Having services that meet the needs of all people on the spectrum would be valued by people who participated in the consultation.

Highlights from the data:

- Almost all of those providing written responses agreed with the proposal to develop a strategy to increase public understanding and awareness.
- Almost all people providing written responses agreed that people with an ASD but who have no intellectual disability should be provided with help to ensure they were able to meet their full potential.

Lifespan – Key services & supports

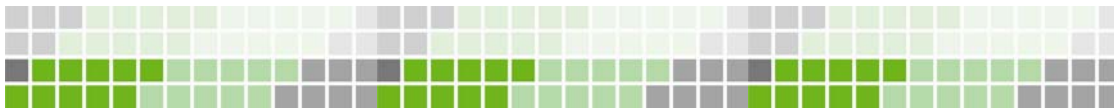
When they turn 18 everything seems to stop...respite stops as it is. Our daughter needs 24 hour care and can't be left alone. How are parents supposed to have a life, let alone the young adult (Family member, written response)?

What have we heard about the range of services needed?

Participants in the consultation process pointed to the broad range of services that are needed at various times throughout their lives by people with an ASD, their families and carers. The importance of these services being provided on an age appropriate, needs basis was a priority for many.

It was further recognised that the precise service and support needs of every individual will alter across their lifespan and that the pattern of this need will differ between individuals.

Particular services mentioned included early childhood intervention, education support, respite, social skills training, behaviour management, employment and accommodation support.



Key messages

A range of specialist and general services, provided by people with ASD expertise, are needed over the lifespan. Because the needs of individuals with an ASD are different, services need to be flexible.

Consultation participants want support to help families and carers do the best they can for the person(s) with an ASD. Individuals with an ASD want support to help them achieve the best they can.

What have we heard about support at times of transition?

At times of transition and change there may be the need for many services to ensure support is available and adequate education of personnel is undertaken (Organisation, written response).

Transition across the life stages – childhood to adolescence, adolescence to adulthood, and adulthood into old age – were viewed as critical times in the life of an individual with an ASD, their families and carers. Appropriate support and information was seen as a priority.

A number of particular transition points were highlighted including identification to diagnosis of an ASD, post-diagnosis, early childhood services to school, primary to secondary school, post school (day programs, tertiary education or TAFE, employment, supported accommodation) and into adult services and later aged care services.

Key messages

Those who participated in the consultation confirmed that transitions can be times when things can become quite stressful and support may not be available. In fact, extra support might be needed during this time because of the particular stress change provokes for the individual with an ASD. Suggestions to improve this situation included early planning for change, an increase in the number and availability of age appropriate services across the lifespan, better coordination of services and good communication between all involved.

Highlights from the data:

Of those providing written responses:

- *Just under half of all submissions specified respite, social skills, behaviour management and sibling support as priority services*
- *Over half of all submissions provided extra written comments about transition and the need for focussed service support*

Lifelong Learning and Participation

People with an ASD need to continue to be challenged and learn, have new experiences ... to achieve their potential (Family member, written response).

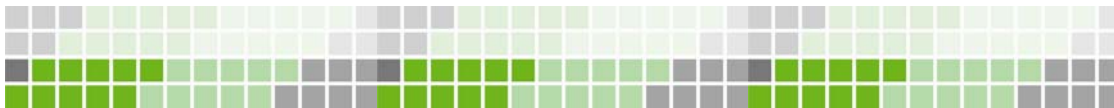
What have we heard about the educational experience?

Education was raised repeatedly throughout the consultation. Participants in the consultation process called for access to high quality, strengths-based educational opportunities for all people with an ASD.

It was frequently noted that modern educational approaches, based on group work, inquiry and discovery based learning can be particularly difficult for students with an ASD. These students often perform better with structured, predictable approaches that make use of visual and electronic support. Some consultation participants reported that children with an ASD were being home schooled due to an unwelcoming or ill-prepared school environment.

Particular mention was made of those students who do not have an intellectual disability and who may perform very well in an 'ASD friendly' academic setting, but who without access to appropriate supports may drop out of education altogether.

There were calls for greater access to support for ASD students within schools including simplification and broadening of access to Program for Students with a Disability Support for students with an ASD.



In particular, better access to specialist educational support for those without an intellectual disability was identified as important.

Consultation participants said that a whole school approach to inclusion was needed – a cultural change in school communities so that schools become ‘ASD friendly’. Better preparation of teachers, use of appropriate teaching methods and greater support for all students with an ASD were all elements of what consultation participants described as ASD friendly schools.

Consultation participants identified a number of ASD friendly schools. These are schools that are pro-active in their approach to ASD students, are flexible with the curriculum and employ appropriate teaching strategies. They are inclusive of parents in planning, 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 individual with an ASD. There was a suggestion that schools could be rewarded for being an ASD friendly school.

Key messages

Education, from early childhood through to adult learning was vigorously discussed by consultation participants with many suggestions about how to build on the good practice that exists and how to improve education for students with an ASD.

There was acknowledgement of the good work of education staff but at the same time a recognition that often staff were not well informed about ASD and not adequately supported to be able to offer the best educational experience to a student with an ASD.

Discussion focussed on the difficulties of students with an ASD who do not have an intellectual disability (ID) and who may not get extra help in the school setting. The lack of extra help may compound the impact of stress and anxiety arising from being misunderstood and in some cases bullied by others. Many respondents drew attention to the critical issues of adolescence when mental health issues are not uncommon as the young person with an ASD becomes increasingly aware of isolation from peers.

Consultation participants want educational settings to be ASD friendly, to be available locally, and to make real the commitment to inclusive education.

What have we heard about employment?

Work provides the opportunity to be a contributing member of society, get out of the house, earn some money, meet some people regularly and gives the person with an ASD the possibility of making friends (Family member, written response).

Early and good planning and support during adolescence followed by access to support during adulthood to assist adults with an ASD gain and maintain meaningful occupation or employment was considered very important by individuals with an ASD and many others. A number of consultation participants spoke of the very valuable contribution people with ASDs, and particularly those with Asperger's could make in the workplace but added that often the difficulties accessing the support needed affected what employment if any, they could take up.

Key messages

Enhancing the opportunities for people with ASD to be employed in either the paid or voluntary sectors begins with good vocational planning during adolescence. Access to that support followed by employment opportunities in adulthood is essential so that people with ASDs can function to their fullest and make a contribution to society.

Some people with ASD may need minimal support to enter the workforce and maintain employment over time. Others will need more intensive support. Notwithstanding, there will be some adults with an ASD who are not able to take up employment.

Just as individuals with an ASD and their family/carers need to prepare for this stage of life, so too do employers and the employment sector who require more information and options as to how to best utilise the skills of people with ASD. The development of a range of supported employment options has been recommended by consultation participants who also provided some excellent examples of good practice.



What have we heard about participation in the community?

One person with an ASD said in their submission that adult 'aspie' groups were helpful and made a real difference – providing a safe and enjoyable social group.

In addition to formal education and work, many participants in the consultation process pointed out that access to appropriate social and recreational activities and life skills support or training is important for people with an ASD.

Access to out of school hours care and school holiday programs which are equipped to care for children with an ASD was also a significant issue for those who cared for school aged children with an ASD.

A number of examples were given of sporting and recreation programs that had made particular efforts to be inclusive of people with an ASD. Respondents reported significant benefits in terms of skills development, confidence and a feeling of inclusion for participants with an ASD.

Buddy systems and mentoring approaches were highlighted as particularly effective service models that assist individuals with an ASD develop life and social skills.

Key messages

Individuals with an ASD have particular contributions to make to society but need understanding and some assistance to do so. Consultation participants suggested that supports including social skills programs in childhood, mentor programs or 'buddies' and support groups through adolescence and adulthood can help people with an ASD engage with others and participate in social and recreational activities.

Highlights from the data:

Of those providing written responses:

- All agreed it was important *in schools where young people and adults with ASD are studying, to make sure that staff are trained and that the organisation is able to support them and help them learn.*
- Almost everyone agreed that it is important to *develop a model with employment agencies and employers that provides a way for employers to support people with an ASD*
- Assistance with the development of social skills to prepare people with an ASD for adult life was emphasised repeatedly throughout the consultation.

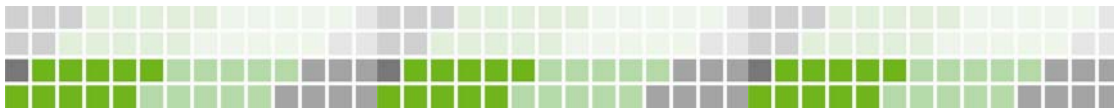
How services should be provided – Quality, equality, consistency, access, timeliness

The front end of information and support service system needs to come to the seeker. Hence, regardless of how complex the system is behind the scenes, to the person requiring services and accessing services it is simple (Organisation, written response).

What have we heard about services and service quality?

While many people spoke highly of support they have received from various services, others described the difficulty they had accessing such services.

There were many people in the consultation who said that above all else there needed to be more services and getting the service needs to be easier. People living in country Victoria said that it was even more difficult for them as there were fewer services and they often had to travel long distances, including coming to Melbourne to services.



Key messages

Consultation participants said that they want high quality, timely, flexible services, staffed by well trained professionals that were available to all people with an ASD and were easy to get. Attention was drawn to the particular service needs for people with an ASD from CALD and indigenous backgrounds. People want services to be delivered 'at the 'right time, in the right place and in the right way'. Flexibility and cultural appropriateness is important as is delivering them in a way appropriate for a person with an ASD to understand and access. Finally the consultation participants said they want to be assured of the quality of the information and services they use.

What have we heard about how the service system works?

There should be more cross-over linking of services. Having to tell your story to so many different departments and agencies is time consuming and emotionally exhausting (Family member, written response).

Many things make a quality service including how well services and professionals work together to deliver services to individuals with an ASD, their families and carers.

Many people spoke of the need for better systems and better working together and information sharing between professionals and services, especially at transitions. Many described the need for an easier way to navigate the service system, including agencies at both the State and Commonwealth level. Contributors made a number of suggestions about ways to make the system work more effectively including local "one stop shops" or regional autism services centres and further development of regional autism provider collaborations such as the Regional Autism Collaborative Teams (ReACTs),

Recent government changes and the creation of the Department of Education and Early Childhood Development are seen as presenting opportunities to streamline and better integrate early childhood services with general education services.

Consultation participants highlighted the diagnostic period as a crucial time when individuals and

families/carers need to be linked in to good information and support. In addition, there was strong support for the proposal in the Consultation Paper that "developing ASD information resources for people of all ages" was important with suggestions that information be available in a range of modes – written, verbal, web-based, DVDs, be evidence-based, trustworthy and provided in manageable 'chunks'.

Key messages

Consultation participants said that it would be helpful if service providers knew more about where to refer families. They also said it would be better if service providers more readily shared information so that the service user didn't have to continually repeat their story.

Contributors were aware that for service providers to be able to work better together they needed good systems to help them, so there were many suggestions about how to make working together easier and communication flow and referral better.

Many people said that a key worker or case manager would be a good way to help them find their way to services, especially early after diagnosis. Finally, many people suggested a regional "hub" to promote good information flow, collaboration, sharing of expertise and referral to appropriate services.

What have we heard about ASD data and research?

What is on the internet about autism often paints the worst case scenarios and can leave a person doing a private search for information very pessimistic and depressed (Family member, written response).

Many agreed that the collection of robust data was vital for service planning, understanding patterns of ASD and understanding what works in service provision. In recognition of this, more than three-quarters of those who made written submissions agreed with the proposal that *ASD be made a reportable condition*. Others however, expressed misgivings about the possibility of this compromising privacy, stigmatising those with ASD or deterring people from seeking diagnosis and support.



Key messages

For the most part, people involved in the consultation agreed that data collection is important for future service planning, but it needs to be done in a way that is respectful of individual privacy.

Australian and international ASD research is important to provide an evidence base for practice and locally relevant ASD research should be fostered and disseminated. Developing systems to monitor and assure the quality of ASD information especially that available via the internet should be considered.

Highlights from the data:

Almost all those providing written responses agreed with the proposals in the Consultation Paper about suggestions to simplify the service system.

The great majority of all written responses confirmed the proposals in the Consultation Paper about ways to improve services and access to services.

Almost everyone responding to the Consultation Paper agreed that it is important to *find out the information and support needs of indigenous people, those who come from a different cultural or language background (CALD) and young people with an ASD.*

Almost all respondents to the consultation paper confirmed that the collection of ASD data was an important issue for inclusion in the State Plan.

Who should provide services – recruiting and retaining a trained, skilled workforce

The teachers have been kind but need much better training and awareness of autism – especially Asperger's Syndrome (Individual with an ASD, written response).

What have we heard about the workforce?

Participants in the consultation process said that more ASD trained professionals and workers were needed across the state in all sectors, including

early childhood, health, education and justice. There were many suggestions from contributors about how to increase numbers in rural areas and how to make specialising in ASD attractive.

The role of the GP received special attention because they are the only professional who may be involved in an ongoing way with an individual with an ASD and their family across the lifespan.

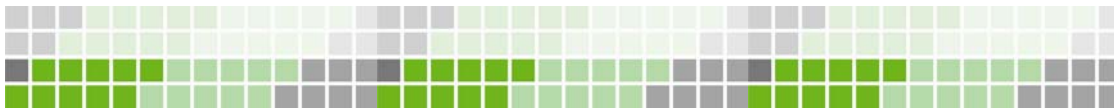
Accreditation of services working with individuals with an ASD was particularly important for some especially with regard to diagnostic practice where respondents spoke of wide variations in skills, approaches and knowledge.

Key messages

The consultation identified support for increasing the number of professionals and workers skilled in ASD and improving or augmenting the undergraduate, postgraduate and in-service ASD training of workers.

A better understanding of ASD and/or specialised training was recommended for many in the workforce including early childhood staff, maternal and child health nurses, respite workers, public transport workers, accommodation staff, teachers, doctors, police, judicial and court officers.

Many people throughout the consultation process talked about service providers who were knowledgeable and skilled in the area of ASD, but there were many mentions of others who were not. The need to better prepare and support professionals and workers for interactions with people with an ASD was emphasised throughout the consultation. Individuals with an ASD, families and carers have an important role in this educative process.



Highlights from the data:

The overwhelming majority of respondents agreed with each of the four proposals in the Consultation Paper to address workforce issues:

- Work with professional organisations to improve ASD skills levels
- Ensure that training and information is suitable/accessible for all
- Continue a secondary consultation service and expand it
- Ensure mentoring of new staff working with people with an ASD

Where to now?

The Partner organisations will continue to develop a draft Autism State Plan. The timeline for achieving this is late 2008 when the draft Plan will be presented to Government for consideration.

The draft Plan will be shaped by the wealth of ideas of those who participated in the consultation processes and information from other sources including local, national and international research and policy and practice innovation.

Particular suggestions and examples of good practice that have been described at the forums or outlined in responses to the Consultation Paper will be followed up during 2008.

Check the website for updates and further information throughout the year:

autismstateplan.dhs.vic.gov.au