

OFFICE OF THE  
PUBLIC ADVOCATE

3 December 2007

Ms Joanna Birdseye  
Senior Project Manager  
Strategic Projects Branch  
Level 20, 50 Lonsdale Street  
Melbourne 3000

**Re: Autism State Plan Consultation**

Dear Ms Birdseye,

The Victorian Office of the Public Advocate welcomes the consultation phase of the Autism State Plan and the opportunity to contribute to this important policy document. It is hoped that the Autism State Plan will result in a more inclusive policy environment and service system for people with Autism Spectrum Disorder.

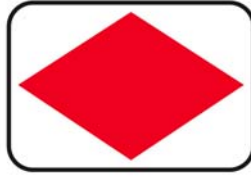
I have attached our submission to this important review. Please contact Janine Bush on 9603 9567 if you wish to discuss any of the issues outlined further.

Yours sincerely,

*Colleen Pearce*

Colleen Pearce  
**Public Advocate**





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## **Submission to the Autism State Plan Consultation Paper**

**3 December 2007**

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# Summary of recommendations

## 1 Introduction

The Office of the Public Advocate (OPA) congratulates the State Government and Autism Victoria on their partnership approach to the development of the Autism State Plan, the strength of which is evidenced by the range and depth of issues and potential actions that have been canvassed in this consultative phase. Both the detail contained in consultation paper and the commitment of the partners to the regional consultations bode well for the future content of the plan.

OPA understands that in developing the Autism State Plan the State Government is meeting its commitment to ‘undertake further work to develop appropriate supports and interventions for people with autism and ensure that government as a whole has a better capacity to respond to people with autism.’<sup>1</sup>

OPA is conscious in reading the consultation paper that Autism Spectrum Disorder (ASD) has not been clearly defined as a disability within the *Disability Act 2006*. Although people with an intellectual disability and/or functional aspects associated with any of the disabilities described by the Act will be covered, many people with ASD will not.

In the absence of a legislative framework that defines the rights and responsibilities of people with ASD and the role and responsibility of government and community in relation to their needs, OPA is concerned to ensure that people with ASD have the same rights and entitlements and receive the same degree of care and protection as other people with disabilities. This submission highlights the importance of focusing on the needs of people with ASD rather than the diagnosis as the main criteria for determining eligibility for support.

It is in this light, that OPA wishes to ensure that the Autism State Plan is founded on a broad and inclusive framework and that there is a strong emphasis in the plan on the right to additional services and protective mechanisms for people with ASD.

## 2 Response to the consultation paper framework and scope

### 2.1 Principles

OPA strongly supports the inclusion of the principles outlined in the Autism State Plan, particularly the emphasis on respect, participation and encouraging the voice of people with ASD.

To further embed these principles, OPA would encourage the expansion of these principles to include explicit recognition of the principles contained within the new *Charter of Human Rights & Responsibilities Act 2006* - most notably, the principles of freedom, respect, equality and dignity. Including these principles would also reflect in the *United Nations Convention on the Rights of People with Disabilities*, 2007 and the *Victorian State Disability Plan 2002-2012*.

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<sup>1</sup> Hansard/second reading Ms Garbutt, Minister for Community Services, ‘Second reading speech: Disability Bill 2006’, Assembly, 1 March 2006.

H<http://www.aph.gov.au/hansard/senate/dailys/ds140305.pdf>H (accessed 3 May 2005)

OPA recommends that the following principles are therefore included in the Autism State Plan<sup>2</sup>:

- i. To promote and protect and ensure the enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.
- ii. The principle of equality recognises that people with a disability are citizens who have the right to be respected and the right to have equal opportunities to participate in the social, economic, cultural, political and spiritual life of the community.
- iii. The principle of dignity and self-determination is about respecting and valuing the knowledge, abilities and experiences that people with a disability possess, supporting them to make choices about their lives, and enabling each person to live the life they want to live.
- iv. The principle of diversity is about recognising and valuing individual difference. Inclusive societies are strengthened by the diversity of their populations and by the contribution that each person makes to the social, economic, cultural, political and spiritual life of society.
- v. The principle of non-discrimination implies that all people have the right to live their lives free from discrimination. This means that society must set right all forms of discrimination – including both active and passive forms of discrimination, and unfair and outdated standards, laws, policies and practices.

## **2.2 Scope**

Part 2, section 4(b) of the *Disability Act 2006* (the Act) identifies the importance of providing a ‘whole of government’ approach to supporting the needs and aspirations of persons with a disability. In Part 5, 6 and 7, the Act outlines protective mechanisms for people with disabilities in relation to (residential and other) disability service providers, prescribing a number of duties, accountabilities and requirements.

Given the lack of a specific reference to ASD in the Act, OPA believes it is important for the Autism State Plan to provide a framework for an integrated, ‘whole of government’ approach to providing services as well as to outline protective mechanisms for people with ASD.

A whole of government approach to the Autism State Plan would ensure a broad and integrated response to ASD. This would include a focus on early intervention, improving opportunities for people with ASD and preventing problems into the future (for example, exposure to the justice system). It would also aim to close gaps in service provision through more effective cross-service linkages, facilitated through flexible funding arrangements.

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<sup>2</sup> Principle i is from the United Nations Convention on the Rights of Persons with Disabilities, article 1 (2006); principles ii – iv are from the *Victorian State Disability Plan 2002-2012*, Department of Human Services. P 9.

OPA's suggested broader framework for the Plan is outlined below.

#### **Integrated Service System**

- Section 1. Early intervention and prevention
- Section 2. Service development, planning, funding and partnerships
- Section 3. Individualised planning and support

#### **Lifestages**

- Section 4. Diagnosis of ASD
- Section 5. Adolescents with ASD
- Section 6. Older adults

#### **Industry Plan**

- Section 7. Strengthening the workforce
- Section 8. Monitoring
- Section 9. Quality improvement

#### **Advocacy, accountability, safeguards, protections**

- Section 10. Advocacy
- Section 11. Protection of rights
- Section 12. Monitoring and implementation mechanisms

**Figure 1. Proposed areas for inclusion in the Autism State Plan**

### **3 Response to key issues outlined in the consultation paper**

OPA acknowledges the thinking that has gone into the consultation paper and notes the range of issues have already been covered therein. OPA is in agreement that the range of issues covering information and support through to pathways, accessing services, diagnosis, transitions, workforce and data have resonance for our client group.

The comments in this submission are informed by OPA's view that ASD is a 'lifelong neurodevelopmental disorder'. That is, ASD is a disability, not a 'mental health condition'. This definition is in concordance with a recent review of evidence, undertaken for the Commonwealth Department of Health and Ageing.<sup>3</sup>

For the purpose of the submission, OPA will focus on service system issues, rights and protections as these are the key issues that we manage on a regular basis providing guardianship and advocacy services.

#### **3.1 Service system issues**

The *Disability Act 2006* identifies the importance of providing a 'whole of government' approach to supporting the needs and aspirations of persons with a disability (Part 2, 4b). OPA would like to see this approach reflected in the Autism State Plan as the need for a whole of government approach is equally the case for people with ASD.

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<sup>3</sup> Roberts, J.M.A., & Prior, M. (2006). *A review of the research to identify the most effective models of practice in early intervention of children with autism spectrum disorders*. Australian Government Department of Health and Ageing, Australia.

*Proposed action 1.* Undertake a ‘whole of government’ approach to service development, planning and funding to ensure a multidisciplinary approach to providing services and supports.

*Proposed action 2:* Work in partnership with support providers to develop an Industry Plan to manage the complex issues pertaining to the workforce including professional development, training, demand management, career pathways, occupational health, safety and quality.

OPA’s experience is of a highly complex and inaccessible service system with many barriers to accessibility including repetitious eligibility testing for people with ASD.

*Proposed action 3:* Establish partnerships/linkages between services to streamline access to services and to avoid repetitious eligibility testing.

In OPA’s experience, there are a range of service system issues that create barriers to accessing services for people with ASD. They include the difficulty in gaining a diagnosis and the lack of an identifiable entry point to autism services.

#### **OPA Case Study**

OPA is the legal guardian for Phuong, a twenty year old man who is described as having ‘high functioning Aspergers Syndrome’ although he has no formal diagnosis. Phuong attended a special school but as a person who was high functioning, he was not provided with optimal educational opportunities in this setting.

Phuong now attends TAFE but was suspended due to inappropriate behaviour. He has several charges relating to arson and theft as he has difficulty managing his behaviour.

OPA and Phuong’s family are concerned that in the absence of the appropriate interventions, his behaviour will continue to get him into trouble, leading to further charges and the risk of incarceration. OPA believe that with an earlier diagnosis and more appropriate support and services, this course may have been averted.

*Proposed action 4:* Provide resources to establish multidisciplinary teams in each DHS region with the responsibility for the screening and diagnosis of ASD.

*Proposed action 5.* Develop a Communication Strategy to raise awareness amongst families and service providers of services that exist.

Complex eligibility criteria, a lack of flexibility of services and the lack of appropriate programs, services and support mean that families and carers of people with ASD may have little idea how to negotiate the system and find the services that they need.

*Proposed action 6.* Encourage stronger links across different service systems to ensure that there are pathways and links between services.

OPA has reflected on the service gaps experienced in working with people with ASD and they include appropriate child care, support in the school setting, accommodation, autism specific adult services, respite care and the affordability of services.

OPA is aware that waiting lists for adult accommodation and support services are extremely long. For example, in the Hume region, where a service for children with ASD is provided on a 4mth rotational basis, there are up to 195 families waiting to access accommodation and school.<sup>4</sup>

*Proposed action 7.* Develop a Demand Management Strategy to ensure that disability supports can meet the needs of people with autism and their families at the individual and system level (as well as to address issues like cost and location of services).

A common experience of people with ASD is falling outside the eligibility criteria for access to services. The former Public Advocate, Julian Gardner, in a key note address at the Australian Guardianship and Administration Committee Symposium, Adelaide 30 April 2004, said that 'some disabilities such as those arising from Autism Spectrum Disorders are not seen as fitting within any of the specialist services'.

OPA's experience validates the point made in the ASP consultation paper regarding service eligibility. That is, criteria used to determine service eligibility is a critical issue influencing access to services. People with ASD may not be able to gain access to services if they fail to meet the definition of 'disability' required for classification under the disability legislation. For example, where autism is not identified before the age of six, a person does not fit the classification of having a developmental disorder.

*Proposed action 8.* Ensure that access to services is based on need and the functional aspects of ASD not on diagnosis.

In addition, the current service system much of which is based on a basis IQ level assessment is limited. People who do not meet the classifications are prevented from effectively accessing existing services. OPA is concerned that the difficulty in gaining a diagnosis paired with the need to meet diagnostic criteria can result in people going into adulthood without access to services, support or treatment.

*Proposed action 9.* Enable service providers to apply more flexible eligibility criteria for use of services to people with ASD and their families.

Part 4, Division 3 of the *Disability Act 2006* specifies that where a person with a disability is receiving ongoing disability services they are entitled to request and receive support planning. OPA is concerned that people with ASD are not entitled by legislation or policy to the same level of case management support as other people with disabilities.

*Proposed action 10.* Make individualised case management support available to people with ASD and their families.

OPA agrees that adolescence to adulthood represents a significant transition point for people with ASD. However, there are many significant transition points for people with ASD where support and planning are required including childhood to young adulthood, the middle years, the transition to independent living and issues related to ageing.

#### **OPA Case Study**

OPA is guardian for Steve, a 19 year old man who has an intellectual disability and ASD. Steve was attending a special school until one year ago. However, when his schooling stopped, DHS were not notified and he was not linked into any services or support. A day placement has not been able to be found for him. His family are unable to manage his behaviour – he has violent outbursts and lights fires. Fear of his outbursts mean that family members do not feel safe in their home yet there are no obvious solutions for managing Steve’s safe transition into adulthood.

*Proposed action 11:* Fund early intervention and prevention services for all transition points using a Lifestages approach.

*Proposed action 12:* Undertake research on good program models for supporting people with ASD through various lifestage transition points (e.g. childhood, adolescence, early adulthood, adulthood, older age).

### **3.2 Advocacy, accountability, safeguards, protections**

In the absence of a legislative framework or policy to define the rights and responsibilities of people with ASD and the role and responsibility of government and community in relation to their needs, OPA is concerned to ensure that people with ASD have the same rights and entitlements and receive the same degree of care and protection as other people with disabilities.

*Proposed action 13:* Propose amendments to the *Disability Act (2006)* to have ASD included along with acquired brain injury and neurological disorders in the definition of disability.

The *Disability Act 2006* provides protective mechanisms for people with disabilities in relation to (residential and other) disability service providers, outlining the duties of residential service providers (Part 5), the rights and accountabilities of service providers (Part 6) and requirements in relation to restrictive interventions (Part 7). OPA is concerned about the impact of ASD not being specifically included in the Act.

*Proposed action 14:* Monitor the impact of the exclusion of people with ASD from the *Disability Act 2006* (particularly in relation to entitlement to services and protection in residential settings).

OPA is of the strong view that protective mechanisms for people with autism warrant inclusion in the Autism State Plan due to the exclusions described above. Issues of importance include strengthening the advocacy sector, ensuring disability supports are more accountable to people with a disability and enhancing protections and safeguards<sup>5</sup>. For example, there are concerns

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<sup>5</sup> The Victorian *State Disability Plan 2002*, p29 ‘Priority Strategy 3’ provides a useful example of the inclusion of these protective mechanisms in policy.

about how well people in residential care services are protected by legislation in relation to their tenancy rights and how behaviour is managed.

*Proposed action 15:* Develop systems to monitor and improve the accountability of disability service providers who accommodate and provide services to people with ASD.

In residential care, educational, community and correctional settings, people with ASD can be subject to the practice of restraint and seclusion due to their behaviour. There appears to be an overuse of chemical restraint and punishment. Where inexperienced staff are providing care, the behaviour of the person with ASD may not be understood and managed appropriately.

Similarly in the corrections system, the needs of people with ASD may not be met because of a lack of understanding of their disability and a lack of appropriate services. This can lead to people being subject to inappropriate sanctions for breaching prison rules. For example, people with ASD are sometimes placed in seclusion as punishment for behaviours that they were unable to control because of their disability<sup>6</sup>. This also applies in Juvenile Justice settings.

*Proposed action 16:* Monitor and regulate the use of restraint and seclusion of people with ASD in educational, accommodation and correctional settings.

The Public Advocate has an important role to play as both guardian and advocate where a substitute decision maker is required. It is important that the option of a substitute decision maker and advocacy are available where needed.

*Proposed action 17:* Monitor the use of advocacy to people with ASD.

## 4 Conclusion

Overall OPA congratulates Autism Victoria and the State Government on the work undertaken so far on the Autism State Plan. In summary, OPA would like to see a focus in the plan on:

- a whole of government approach to service development, planning and funding to providing services and supports;
- additional resourcing to increase the availability of services; and
- ensuring that people with ASD receive the same level of services and the same rights and entitlements and degree of care and protection as other people with disabilities.

OPA is happy to contribute in any way to the further development of the Autism State Plan.

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<sup>6</sup> Office of the Public Advocate, *Submission to review of Disability Discrimination Act 2003*