



## **Autism – Stop the Robbery**

**Priorities for the 2010/11 Victorian State Budget**

Holding Government accountable to the Autism State Plan vision and six priority areas of action.

**AFSA**  
**16th Nov 2009**

The Honorable John Lenders  
Treasurer,  
1 Treasury Place  
East Melbourne Vic 3002.

16<sup>th</sup> November 2009

Dear Minister Lenders,

Re: Autism – Stop the Robbery - Priorities for the 2010/11 Budget

The Autistic Family Support Association Inc. (AFSA) represents individuals with an ASD, their parents/carers and families.

AFSA is an incorporated, self-funded, statewide, voluntary, parent based support group, and is a member of Autism Victoria. Through systemic advocacy our aim is to improve the outcomes and quality of life for individuals with an Autism Spectrum Disorder (ASD) and their families and carers. We are not a funded agency.

We do not consider that autism is a disability any better or worse than any other disability, but it is different, is not well understood and is an emerging problem for a number of reasons.

Government should be provoked in to action given that Research findings are that ASD's have a genetic basis and anecdotally it seems that each generation is more affected than the previous.

Because preventative services such as intervention services (early childhood or other), school supports, support services, respite and accommodation options are inadequate and in many cases absent, costs to Government and the community are inflated in the areas of Juvenile Justice, Mental Health, Homelessness, Drug and Alcohol abuse and so on.

*Autism is associated with burden and stress for parents (Howlin et al., 2004). The demands placed upon parents caring for a child with autism contributes to a higher overall incidence of parental stress, depression, anxiety and adversely impacts upon family functioning and marital relationships compared to parents of children with other intellectual, developmental or physical disabilities (Dunn et al., 2001;Yim et al., 1996) (Tonge, Brereton, et al, 2006).*

AFSA has actively supported and participated in the development of the Autism State Plan which was launch 21st May 2009 and received initial funding of \$8.3m. We maintain an active role as a member of the stakeholder implementation group.

We concur with the Autism State Plan (ASP) vision ***“All people with an ASD and their families are supported to fulfil their maximum potential, enjoy life and contribute to their community”*** and support its six priority areas being:--

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

Priority areas 1, 2, 3 are also integral to achieving priority 4 & 5.

Notwithstanding this, it is evident that the needs of families of people with an ASD are not being adequately met due to a lack of sufficient funding across the developmental ranges and stages.

AfSA holds Government accountable to the upholding of the ASP vision and priority areas of action.

There is no doubt that the burning issues for the autism community are:-

- Education support services and appropriate education settings. The education issues are across both Government and non-government schools.
- access to the full range of disability support services including respite and accommodation options;

An extract from the report *The State of Victoria's Children*

<http://www.education.vic.gov.au/about/directions/children/annualreports.htm>

*Outcomes data in relation to children with a disability, CALD children and children in out-of-home care continue to be limited, and this is particularly so in respect of Victorian data. Available data suggest that outcomes for children in these groups are generally poorer than for the general child population. However, as shown below, this is not the case for all indicators:*

- *Australian research shows that a considerable proportion (around 63 per cent) of children with a disability experience difficulties at school. In Victoria, around 20 per cent of people aged over 15 years with a disability have not attended school or have only progressed to Year 8, compared to 5 per cent of the general population, and only 55 per cent of people with a disability are employed, while over 81 per cent of the total Victorian population is in paid work.*

The Education Department's mandate of "every child, every opportunity" cannot be achieved whilst many of our ASD students, remain ineligible to access supports under the program for students with a disability resulting in many adolescents with an ASD having very poor outcomes.

Whilst an initial investment has been made, AFSA holds the Government accountable to deliver what The Autism State Plan says: about priority area 4

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

### Why is this a priority?

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

To get the most out of their schooling, students with an ASD need assistance. Teachers may also need assistance in the classroom or training to ensure that students with an ASD get a high quality educational experience. Better preparation of teachers, use of appropriate teaching methods and greater support for all students with an ASD are important to ensure that this group of young people are able to benefit from their educational experience.

### Action Required:-

\$20m over 10 years to increase the quantity of Early Childhood Intervention services available to those with ASD and high and complex needs.

\$10m over 4 years to enable 1 EFT ASD expert consultant for every network throughout Victoria.

\$10m over 4 years recurrent to enable additional staff resources to schools to support students with and ASD not currently funded under the Program for students with a disability.

# 91:

**8:26 pm PDT, Aug 9, C Grujic, Australia**

MY 9 year old son has ASD and recieves no funding at school. They just ignore his needs completely. We need help!

Yes, the A.S.P. needs more funding. Educating our children is a major priority and the current system is failing us terribly. It's a disgrace

A quote from our online petition

We are thankful for the State Government's recognition that Autism Spectrum Disorders are a disability and welcomed the change in December 2008 to the Disability Services access policy. Those desperately needing services once deemed ineligible with an ASD who don't also have an intellectual disability, such as those with Aspergers syndrome are now deemed eligible to request a service.

*Life Transition Problems : Young People with Autism Spectrum Disorders*

*Key Finding:-*

6. *Approximately 30% of young adults with HFA or Asperger's Disorder do not have a day programme, school or work placement*

7. *Approximately 50% of young people with an ASD do not receive any help with the process of transition from either primary to secondary or secondary to post school options which impacts adversely on their mental health. The most critical transition help is from primary to secondary school and is associated with subsequent lower rates of mental health problems*

*All of the key findings of this report can be found at appendix 1*

Accessing the range of support services is very difficult for most within the autism community. In particular appropriate, respite services, including residential options. Furthermore, through the process of the Autism State Plan, the issue of appropriate accommodation options was not raised frequently, simply because aging carers are beyond consultation processes, hence AFSA's elevation of this as a priority.

Many current models of service such as respite are not appropriate for the autism community, and whilst there has been some investment in Disability Support services, the "pointy end" of access to services remains too pointy. Only those in crisis have a small chance of accessing a service.

It would make more sense to break the cycle of managing chronic crisis through adequate investment, enabling opportunity for successful participation in the community.

We support the Autism State Plan's vision for support.

### A vision for support

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

#### The Plan's aims

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

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

### Achieving the vision

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

*Action Required:  
\$2.7m over 4 years to build 3 residential respite facilities in each of the 9 regions for people with an ASD.*

*\$5m over 4 years for additional respite staff*

*\$4m over 4 years for recreational services*

*\$10m over 4 years for ASD Hubs*

We thank you for taking the time to read this submission and seek your urgent consideration of the priorities of families of children with autism when determining your priorities for the 2010/11 Budget.

We welcome the opportunity to discuss these priorities with you at your convenience.  
Yours sincerely



Meredith Ward  
President  
0400 226 408

# 51:

**5:50 pm PDT, Jun 23, Karen Lunney, Australia**

Our most committed volunteer in the youth ministry office has autism, and I know that support services are needed to ensure that he and others have the care that is needed.

A quote from our online petition

## Appendix 1

### Life Transition Problems : Young People with an Autism Spectrum Disorder.

#### Key Findings

The findings of both the quantitative and qualitative studies give rise to a number of implications for practice and service delivery, particularly with regard to the need to improve the availability, access, timeliness, equity, continuity, coordination and integration of services provided to young people with an ASD and their families. Information from service providers supported these findings and acknowledged the lack of ASD specific training for professionals working with children and young adults with an ASD and their families.

1. Mental health problems in young people with an ASD are prevalent
2. Those with HFA and AD experience high levels of psychopathology
3. Parental mental health problems are significantly greater than for parents of children with ID and the general population
4. Family dysfunction is significantly higher than the general population for all families with a child with an ASD
5. Reduced quality of life, burden of disease and high cost to the individual, family and community are associated with all ASDs, particularly for those who also have mental illness, are female, and are greater than for disability in general
6. Approximately 30% of young adults with HFA or Asperger's Disorder do not have a day programme, school or work placement
7. Approximately 50% of young people with an ASD do not receive any help with the process of transition from either primary to secondary or secondary to post school options which impacts adversely on their mental health. The most critical transition help is from primary to secondary school and is associated with subsequent lower rates of mental health problems
8. Behaviours (antisocial) which might involve the police or courts are common in young adults with an ASD. Further research into this problem is needed
9. Health and mental health care for young people with an ASD is patchy at best and clinicians lack expertise
10. Despite the critical relationship between parents and teachers, there is no planned method of regular communication between parents and teachers for all children and young adults with an ASD
11. There is no service plan across the life span prepared by a multi-disciplinary group (health, education, housing and welfare) including the parents that is regularly reviewed and available for young people with an ASD and their families.
12. Case management is not available to all young people with an ASD.
13. All professionals, teachers and care workers who provide services to young people with ASDs currently do not receive ASDs specific training
14. Currently, there is no accreditation process for people delivering ASDs training
15. There is no single point of reliable and evidence-based ASDs information and services

Prof Bruce Tonge, Dr Avril Brereton, Ms Kerry Bull  
June 2008