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1st September 2006

The Honorable Mr. Steve Bracks,
Premier,
1 Treasury Place
Melbourne Vic 3002

Dear Mr. Bracks,

Re: Election Priorities

Autism Victoria Inc. represents individuals with an Autism Spectrum Disorder (ASD), parents/carers and ASD Specialist Service providers. Our federation of organisations^(a) means Autism Victoria Inc. is the gateway to Victoria's ASD Specialist Services and ASD expert professionals^(b). We are also Victoria's unified voice of service users and ASD specialist service providers.

Prevalence of ASD's is now 1:166^(c) (60 per 10,000) a rise of about 1100% from the 1 in every 2000 (5 per 10,000) cited a decade ago. Yet funding for assessment, diagnostic, intervention and support services across the life cycle have not kept up with the increased demand for services.

The Early Childhood Intervention Services (ECIS) sector in particular is in crisis because there has only been a slight easing of demand pressures through modest increases to the number of funded ECIS places since your Government's first budget. There has been no re-assessment of the unit cost for ECIS services despite the model of service delivery being broadened from a child focused therapy model to a "social" model that is family focused and includes a suite of services including parent support and education services, and transition to kinder and school.

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).^(d)

Currently individuals of all ages with an ASD and their families do not receive access to a basic level of service because of the gaps created by inadequate funding and in some cases an absence of funding for services. The level of services offered fall well short of best practice.

We seek a meeting with you and relevant Ministers to discuss the issues affecting the autism community. We are confident that a significant positive impact upon the outcomes of individuals and their families is achievable through appropriate investment and co-ordination of existing services.

We thank you for considering the concerns of Victoria's Autism Community and look forward to working in partnership with you to develop effective whole of Government policy.

Yours sincerely

A handwritten signature in blue ink that reads "Meredith Ward".

Government and Public Relations Liaison

CC: The Honorable Jacinta Allan MP
CC: The Honorable Sherryl Garbutt MP

Summary - Overview of Current Situation & Actions Required

Meeting the needs of all Victorians with Autism Spectrum Disorders
Total Package \$44.381m p.a. including Recurrent funding of \$41.481m p.a.

Overview - Current Situation	Action Required
<p>ASD – State Plan – Not Funded.</p>	<p style="text-align: center;">ONE</p> <p>New one off funding \$ 50,000.00 pa. for 3 years (total \$150,000.00) A state plan by Autism Victoria would be developed through a collaborative statewide Whole of Government approach in response to increased demand for ASD specialised services within mainstream generic and special settings.</p>
<p>“Autism Spectrum Disorder” (ASD) as a discrete disability.</p> <p>ASD is not recognised in policy or legislation as a discrete disability. Individuals with an ASD but without an intellectual disability are generally not eligible for services.</p>	<p style="text-align: center;">TWO</p> <p>Inclusion of the term “Autism Spectrum Disorder” as a discrete disability in policy and legislation.</p>
<p>ASD Multidisciplinary Diagnostic Service Teams – Currently Not Funded Current assessments conducted by various teams and private practitioners. Process for family from identification to diagnosis can take several months. Assessment process face-to-face about 3+ hours for child/family plus about 15 hours report writing and consultation by professionals. Team assessment costs about \$1300.00 ea. Assessment protocol and pathways available from Autism Victoria.</p>	<p style="text-align: center;">THREE</p> <p>New recurrent funding of \$1.296m pa. for Multidisciplinary Diagnostic Service Teams to provide an extra 2 assessments per week per region p.a. (48 weeks)</p>
<p>ASD Specialist Early Childhood Intervention Services – Current Budget about \$34.2m p.a. Total of 8670 funded ECIS places About 4470 NGO places @ about \$4800.00 ea p.a. which provides about one direct contact hr/week of service for about 40 wks p.a. plus 4200 SCS places @ about \$2000.00 ea. p.a.</p>	<p style="text-align: center;">FOUR</p> <p>Increase recurrent funding by \$ 30m pa. to create 1000 new “Enhanced” ECIS places @ \$30,000 ea. p.a. (40 weeks) and expand services to include transition to school services to the age of 8 years.</p>

<p>ASD Specialist Service Centres- Currently not funded 5 ASD specialists exist need expansion (Irabina(EMR);Gateways(B);Noah's Arc West (WMR);Kalparrin(NMR)Mansfield TTS 3 with ASD expertise could be enhanced (Bendigo EI (LM);Mpower(SW);Pinarc(G) 1 new required Gippsland 1 new required Hume</p>	<p>FIVE New one off funding of \$2.25m to enhance established ASD specific agencies and create new ASD specific agencies where required hence providing an ASD Specialist Services Centre in each of the 9 DHS Regions.</p>
<p>“Whole of Life” Statewide ASD Training Strategy- Current budget about \$1.0m. + About 3% of ECIS budget is used for community development. \$400,000 /4 years ASD ACT NOW project concludes June 2007. ECIS professionals currently provide consultation to professionals across a range of disciplines including Early Childhood, Education; GP; Paediatrics</p>	<p>SIX Increase re-current funding by \$1.8m to provide \$200,000 pa. to each ASD specialist service centre per DHS region for secondary consultation and training and mentoring across the life cycle and professional disciplines.</p>
<p>ASD Educational Support - Current Budget about \$333.6m program for students with a disability (PSD). Current ENQ does not cover all children with an autism spectrum disorders. It does not recognise Aspergers Syndrome or PDD-NOS.</p>	<p>SEVEN Increase re-current funding for PSD by \$8.0m p.a. to meet the needs of students who would become eligible under an amended ENQ ASD criteria to accurately reflect all children with an ASD including Aspergers Syndrome & PDD- NOS (based on 800 places @ \$10,000.00 ea. p.a)</p>
<p>ASD Specialist Adult Lifestyle Support Program – Currently Not Funded</p>	<p>EIGHT New one off \$600k plus new re-current \$250k pa. would establish a Lifestyle Planning and Support service for Adults with and ASD and provide a Learning and Development Service that can provide training to community groups, service providers, and government departments to improve the integration of adults with an ASD into the wider community.</p>
<p>Service planning and co-ordination for Adults with and ASD who do not have an Intellectual Disability – Currently Not funded.</p>	<p>NINE New re-current funding of \$135,000.00 p.a. would provide 1 part-time service planning and co-ordination position for each DHS region for Adults with an ASD but no I.D.</p>

1. Development of an ASD State Plan

Prevalence of Autism Spectrum Disorders in the community is now 1:166 ^(c) (60 per 10,000) a rise of about 1100% from 1 in every 2000 (5 per 10,000) cited a decade ago, placing considerable strain upon diagnostic, intervention, educational and support services across all life cycle phases.

In addition, a move over the past decade from exclusive settings to inclusive models within early childhood, childhood and adulthood means there is an increased need for Specialist knowledge in mainstream generic settings such as kindergarten, childcare, primary, secondary and tertiary education facilities as well as continued specialist support to specialist settings. There is also a need for greater understanding and awareness amongst allied and acute health professionals.

Because babies with an ASD grow into adults with an ASD, the services they require traverse the Bureaucratic silos. Hence, the need for a coordinated statewide response is now urgent especially when you consider that the inclusive “social” model is beginning to mature and the “pioneer” children with an ASD are beginning to enter Secondary and Tertiary Educational facilities.

Autism Victoria Inc. is well placed to work collaboratively with Government to develop a statewide co-ordinated response to the increased demand on services across the life cycle. An ASD state plan would include evaluation of the current situation, identifying the strengths and weaknesses of various sectors, service gaps, and consider the findings of the ACT NOW project about the ASD specialist knowledge, skill and expertise needs of professionals across all sectors.

Action required:

***New One Off funding of \$50,000.00 p.a. for 3 years. (Total Investment \$150,000.00)
Development of an “ASD State Plan” by Autism Victoria through a collaborative statewide Whole of Government approach in response to increased demand for ASD specialised services within mainstream generic and special settings.***

2. Recognition of “Autism Spectrum Disorder” as a discrete disability

“Autism Spectrum Disorder” is the umbrella term encompassing the three diagnostic terms **Autism, Aspergers,** and **PDD-NOS**. Despite some individuals having an IQ within the “normal” range (above 70) individuals with a diagnosis within the spectrum of disorders have significant impairments within three main areas of their functional ability. (i.e. communication; socialization; restricted, repetitive and stereotyped patterns of behaviour, interests and activities.).

Current legislation, policy and service delivery deems individuals without an intellectual disability ineligible thereby disadvantaging those members of our Community. Recognition and inclusion of “Autism Spectrum Disorder” in policy would eliminate discrimination and allow access to services and supports currently denied to people with an ASD who have an IQ within the normal range.

Action Required:

Inclusion of the term “Autism Spectrum Disorder” as a discrete disability in policy and legislation.

3. Diagnostic Services

Whilst ASD is present at birth, children are generally diagnosed with an ASD by about 3 years of age, whilst many others are diagnosed once they enter the education system. Increasingly, adults are also being diagnosed.

At present diagnostic services are conducted by various teams in various arenas. E.g CAMHS, Gateways Support Services in the Barwon region, some Universities also have diagnostic teams. In addition, private practitioners conduct diagnostic services. Whilst ASD specialist Irabina Childhood Autism Services has the capacity to undertake diagnostic services and offers a limited number on a “fee for service” basis, it is not funded to offer such services to families who are unable to pay privately.

According to the recent report, *Autism in Victoria (AIV)*, families are waiting up to three years to access diagnostic services. Investment in ASD centres like Gateways and Irabina to expand their services would build the diagnostic capacity within the sector and relieve pressure of diagnostic waiting lists. A number of CAMHS teams also have developed a level of ASD expertise and require specific funding to reduce waiting lists for their diagnostic services.

Because of a lack or in some cases an absence of diagnostic services, some families are forced to travel to Melbourne to access private services at great personal expense, financially and emotionally. Whilst absence of diagnosis does not necessarily prevent access to some services, timely diagnosis is the key to identifying and meeting the needs of families. Therapeutic interventions and support services must be tailored to address the deficits of a child's functional abilities and meet the global needs of the family.

The AIV report says: “The assessment/diagnosis process should be as early as possible to minimize waiting time for the child and family. Formal diagnosis need to be conducted by a multidisciplinary team covering communication, socialization, and language, including rigidity of thought, motor behaviours and other ritualistic behaviours of the child....”

Action Required:

New recurrent funding of \$1.296m for Multidisciplinary Diagnostic Service Teams to provide an extra 2 assessments per week per region p.a. (48 weeks)

4. ASD Specialist Early Childhood Intervention Services

Experts like Prof. Margot Prior AO, agree that the early childhood years are the critical period of brain development. This is the time of a child's development when they should be receiving life changing treatment and therapeutic intervention services.

A suite of intervention services is crucial to improving the outcomes of children and is only available to children/families up to the age of 6 years or school entry. This limited window of opportunity to reduce the impact autism has upon a child's functional ability is further reduced by waiting lists of 18 months or more. This places the child/family with an ASD at a distinct disadvantage compared to a child whose disability is identified at birth or soon after.

So great is the pressure of waiting lists that NGO's provide services beyond the number they are funded for resulting in reduced “intensity”. The ECIS sector is in crisis because of demand pressures (about 12,000 children* in the 0-4 year cohort with a severe/profound

disability (all disabilities) v's 8670 funded places.) combined with the expansion of services from a therapy focus to service co-ordination and a total absence of core funding increases. Modest increases to ease demand fall well short of the 1100% increase in ASD prevalence.

Experts agree that best practice for children with an ASD means providing on average about 20 hours min. per week of ECI services by professionals with autism expertise in appropriate environments. Using the current DHS Output Based Funding formula 15 hours per week of ECI services would cost about **\$30,000.00 p.a. (approx) per child.**

The AIV report recommends: *"Timely, effective early intervention for children in Victoria with probable or diagnosed ASD"*

* source: Association for Children with a Disability

Action Required

Increase recurrent funding by \$ 30m to create 1000 new "Enhanced" ECIS places @ \$30,000 ea. p.a. (40 weeks) and expand services to include transition to school services to the age of 8 years.

5. ASD Specialist Service Centres

At present we have a number of established Autism specific agencies that provide autism specific services to families and secondary consultation and training to other services. The AIV report says "Support programs including the education of parents, sibling support programs and transition support programs could be co-ordinated at the regional level by the existing autism specific service providers. ..". Major findings of the AIV report recommended: *"A continuum of coordinated services at the regional/local level" This is based on AIV report assumption (ii) Services should be available to all with ASD as early as possible, and the services should be directed towards ensuring optimal ongoing social, communication, behavioural and educational opportunities for the child and on-going appropriate support for the families.*

Gateways (Barwon), Irabina (EMR), Noah's Arc West (WMR), Kalparrin (NMR); and Mansfield (statewide) already provide ASD specialist services. Mpower (SW), Pinarc (G) and Bendigo EIP (LM) are ECIS providers with a level of ASD expertise to build on. The Hume and Gippsland regions are the only regions that require establishment of an ASD specialist centre from the ground up, however there are ECIS providers in these regions whose services could be enhanced and expanded to become ASD specialist centres. The quality and integrity of ASD specialist services could be maintained through the development of Autism Victoria mechanisms.

Action required

New one off funding of \$2.25m to enhance established ASD specific agencies and create new ASD specific agencies where required hence providing an ASD Specialist Services Centre in each of the 9 DHS Regions.

6. “Whole of Life” Statewide ASD Training Strategy for professionals

The organizational members of Autism Victoria are the key employers of ASD specialist professionals. Industry experts agree that because of the pervasive nature and complexity of the disorder, ASD expertise can only be gained by working with large numbers of children with an ASD over a period of time, hence the need to invest in secondary consultation and training strategies through these organisations.

The AIV report says “Key issues raised by service providers include difficulties with staff recruitment and retention of those with specialist experience in working with children with ASD, inadequate provision of professional development, lack of community education, knowing about ‘best international practice’ and implementing strategies that are most appropriate for the child with ASD. Many services reported that their staff, although dedicated, eventually burn out and then seek employment in higher paid occupations.”

The AIV report supports the use of Autism specific service providers to co-ordinate and mentor all other early childhood intervention services. *The AIV report recommends: “Education for service providers and the wider community about the needs of children with ASD and their families.*

Action Required:

Increase re-current funding by \$1.8m to provide \$200,000 pa. to each ASD specialist service centre per DHS region for secondary consultation and training and mentoring across the life cycle and professional disciplines.

7. ASD Educational Support

At present the Victorian Education Dept does not recognise Aspergers Syndrome, despite it now being on the Federal Government list of “Recognised Disabilities”. Prevalence of ASD in the community is about 0.6% of which about 70% of that population will receive a diagnosis once they enter the education system. About 30% (of the 70%) will have an ASD but no intellectual disability and hence are usually not eligible for educational support under the ASD, severe language or severe behaviour categories.

Many of these families struggle through the educational system and in many cases remove their child from formal educational settings altogether. Changing the ASD criteria within the Educational Needs Questionnaire (ENQ) to include all children with an ASD would allow schools to implement appropriate supports to meet every child’s educational needs. There would need to be a modest budgetary increase to meet address the impact.

Action required:

Change the ENQ ASD criteria to accurately reflect all children with an ASD including Aspergers Syndrome & PDD- NOS and increase re-current funding by \$8.0m to meet the needs of students. (based on 800 places @ \$10,000.00 ea. p.a)

8. ASD Specialist Adult Lifestyle Support Program

Toddlers with an ASD grow into Adults with an ASD and whilst there are some specialist services for the early childhood sector, and some funding for day programs and respite services, there are no funded services for community-based support for adults with an ASD.

Action Required:

New one off \$600 k plus new re-current \$250k would establish a Lifestyle Planning and Support service for Adults with and ASD and provide a Learning and Development Service that can provide training to community groups, service providers, and government departments to improve the integration of adults with an ASD into the wider community.

9. Service planning and co-ordination for Adults without and Intellectual Disability.

Currently there are no service planning or co-ordination services for adults with an ASD who have an IQ within the normal range - (above 70) as they are not recognised under the Intellectually Disabled Persons' Services Act 1986 deeming them ineligible for services.

Action required:

New re-current funding of \$135,000.00 p.a. would provide part-time service planning and co-ordination for each DHS region for Adults with an ASD who do not have an intellectual disability.

Appendix – Footnotes from page 1

(a) = Autism Victoria Organisational Members:-

- ◆ Illoura Early Childhood Intervention Services (ECIS Provider to age 6 years)
- ◆ Southern Autistic School (ASD Special Development School to age 18 years)
- ◆ Irabina Early Childhood Autism Services (ASD specialist ECIS Provider to age 6)
- ◆ Autistic Family Support Association (non-funded parent to parent support)
- ◆ Gateways Support Services (ECIS and other support up to 18 years Generic & ASD)
- ◆ Western Autistic School (ASD specialist SDS)
- ◆ Wantirna Heights School (ASD specialist SDS to age 12 years)
- ◆ Alpha Autism (ASD adult services)
- ◆ Autism Behavioural Intervention Association (private ASD provider)
- ◆ Bulleen Heights School (Dual mode special school to age 18 – including specialist ASD programs for primary age)
- ◆ Statewide Autistic Services (adult residential and day programs, children's respite service)
- ◆ Mansfield Autistic Centre (short term residential school for rural families and traveling teacher service)
- ◆ Kalparrin Early Childhood Intervention Program (ECIS provider to age 6 years)

The Autism Victoria State Council comprises a representative from each of the above plus three Elected and five Co-opted members.

(b) = Autism Victoria Professional Panel:-

Dr. Amanda Richdale (Senior Lecturer School of Health Sciences RMIT University); Dr. Cheryl Dissanayake (Senior Lecturer School of Psychological Science La Trobe University); Val Spence (Kalparrin ECIS Generic & ASD) Dr Ric Haslam (Consultant Paediatrician Austin Health); Jacqui Borland (Irabina ASD ECIS & Education), Lesley Matthews, (Social Worker Karinya Counselling), Sally Girvan (Dietician), Dr. Lawrence Bartak (Psychologist), Meredith Ward (Government & PR Liaison, Autism Victoria)

(c) = Prevalence report:-

Pervasive Developmental Disorders in Preschool Children: Confirmation of High Prevalence.

Chakrabarti S, Fombonne E.

Department of Psychiatry, Montreal Children's Hospital, 4018 Ste-Catherine West, Montreal, QC H3Z 1P2, Canada. eric.fombonne@mcqjill.ca.

OBJECTIVE: The rate of reported pervasive developmental disorders has increased, and the authors found a rate of 62.6 per 10,000 in a previous study of preschoolers in Stafford, U.K. They conducted another survey in 2002 to estimate the prevalence in children in a later birth cohort and to compare it to previous findings from the same area. **METHOD:** Screening for developmental problems included 10,903 children ages 4.0 to 6.0 years who were living in a Midlands town on the survey date. Children with symptoms suggestive of pervasive developmental disorders were intensively assessed by a multidisciplinary team using standardized diagnostic interviews, psychometric tests, and medical workups. **RESULTS:** Sixty-four children (85.9% boys) were diagnosed with pervasive developmental disorders. The prevalence was 58.7 per 10,000, with a 95% confidence interval (CI) of 45.2-74.9, for all pervasive developmental disorders, 22.0 per 10,000 (95% CI=14.1-32.7) for autistic disorder, and 36.7 per 10,000 (95% CI=26.2-49.9) for other variants. These rates were not significantly different from the previous rates. The mean age at diagnosis was 37.8 months, and 53.1% of the children were originally referred by health visitors. Of the 64 children with pervasive developmental disorders, 29.8% had mental retardation, but

this rate varied by disorder subtype. Few children had associated medical conditions.
CONCLUSIONS: The rate of pervasive developmental disorders is higher than reported 15 years ago. The rate in this study is comparable to that in previous birth cohorts from the same area and surveyed with the same methods, suggesting a stable incidence.

(d) = 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).

Tonge, B., Brereton, A., Kiomall, M., Mackinnon, A., King, N. & Rinehart, N. (2006). Effects on parental mental health of an education and skills training programme for parents of young children with autism: A randomised controlled trial. *Journal of the American Academy of Child and Adolescent Psychiatry*. 45 (5): 561-569.

Dunn M, Burbine T, Bowers C, Tantleff-Dunn S (2001), Moderators of stress in parents of children with autism. *Community Mental Health Journal* 37: 39-52

Howlin P, Goode S, Hutton J, Rutter M (2004), Adult outcome for children with autism. *J Child Psychol and Psychiatry* 45: 212 - 229

Yim SY, Moon HW, Rah UW, Lee IY (1996), Psychological characteristics of mothers of children with disabilities. *Yonsei Medical Journal*, 37: 380-400

Additional Information :-

The *Autism in Victoria* Report was commissioned by the Dept. of Human Services and conducted by La Trobe University. It can be downloaded at:-

[http://www.office-for-children.vic.gov.au/children/ccdnav.nsf/fid/-7609B41365F051B3CA25700A001C34F5/\\$file/autism in vic.pdf](http://www.office-for-children.vic.gov.au/children/ccdnav.nsf/fid/-7609B41365F051B3CA25700A001C34F5/$file/autism%20in%20vic.pdf)

Autism Victoria Inc. www.autismvictoria.org.au

ASD ACT NOW project Monash University.

<http://www.med.monash.edu.au/spppm/research/devpsych/actnow/download/bruce-tonge.pdf>