

## **Deliver Better Health Results**

# ***BETTER SERVICES AND SUPPORT FOR CHILDREN WITH AUTISM AND THEIR FAMILIES***

### **What the Tasmanian Liberals will do:**

**Provide a staged, evidence-based and long-term approach to provide screening, diagnosis, early intensive treatment services for children with autism, including support through the education system**

The Tasmanian Liberals commit to a staged, long-term and evidence-based approach to establishing early screening, diagnosis and early intensive treatment for children with autism.

### **Screening, diagnosis and early intensive treatment services**

Under the first year of a Liberal Government, we will –

- Introduce early screening for autism at 18 months and two years of age. This will be performed by child health nurses, GPs and paediatricians who will be trained in the use of the simple, easy-to-use but effective early-screening tool, CHAT (Checklist for Autism in Toddlers).
- The CHAT tool will also provide the modelling and demographic data needed for the development of early intensive treatment services across the State.
- A child that has autism will display clear evidence of this before the age of three years. If a child fails the CHAT test once, health professionals are advised to re-screen one month later, then if failure persists, the child is referred to a diagnostic panel.
- The CHAT test is a 5-10 minute test with a 90% accuracy in detecting autism. It has been extensively evaluated<sup>1</sup> and found to be an effective early screening tool. It is in use around most countries around the world.

In the second year of a Liberal Government, we will –

- Set up a diagnostic panel for those red-flagged by the early screening tool, so that those children can undergo full diagnosis. The panel will be required to use world best practice principles, including test for co-morbidities such as epilepsy, fragile X, tuberous sclerosis and genetic screening. As some of this testing will be required at the hospital-level, professional training of hospital staff to deal with children with autism will take place.

---

<sup>1</sup>

Journal of the Royal Society of Medicine, October 2000, Volume 93.

- The panel will be required to draw up individual treatment programmes specific to the child. The panel will be made up of a psychologist, speech therapist and paediatrician with experience in autism.
- The panel must agree upon the diagnosis before the child is referred to the Early Intensive Treatment Centre in Hobart.

In the third year of a Liberal Government –

- The first Early Intensive Treatment Centre will be established in southern Tasmania. This Centre will include intensive treatment for up to 20 children who will have access to psychologists and speech therapists although the majority of treatment will be undertaken by trained behavioural therapists.
- The Centre will not be a day centre or child-minding exercise. It is based on the evidence-based premise that intensive early intervention and treatment are needed *before* the child commences school, so is able to cope in a school environment.
- All children will have individually tailored programs of approximately 20-30 hours of Applied Behavioural Analysis (ABA) therapy a week.
- The Centre will also provide rehabilitation and treatment for children who are not currently coping in the existing school system.
- The Centre will provide for professional development and learning opportunities, including parents, teachers and teacher aides. It will be accessible to the University of Tasmania for graduate teachers, psychologists and allied and other health professionals, including child health nurses and speech therapists and a Hodgman Liberal Government will discuss with the University additional possibilities for autism education.
- The Centre will continue to support the child in his/her transition to primary school.
- Withdrawal areas will be provided in all primary schools, and staff from the Centre will provide assistance to schools when needed. This will allow for continuity for the child and his/her individually tailored program.
- The Centre will provide outreach, where possible, to children, families and schools throughout southern Tasmania.
- Subsequent centres will be established in the North, North-West and an additional centre in the south in subsequent years.
- The Centre will be staffed by trained psychologists as well as therapists who are trained in delivering ABA treatment.

To implement this staged approach to better services and support for children with autism and their families, a special task force will report direct to the Minister for Human Services and Minister for Education.

The Task Force will ensure ongoing evaluation of the first Early Intensive Treatment Centre and make recommendations to government on the placement of subsequent centres throughout the State.

### **Support for students with autism in high school**

A Hodgman Liberal Government have already committed to providing an additional \$1.3 million for the A-team (Autism) program which will fund the continuation of the program in the north and see it rolled out across the State for a three-year trial.

Evidence from parents, teachers and students is that the A-team works with high school children with autism, who have either dropped out of school, or only have access to distance education, or are struggling to cope with the noisy and ever-changing environment of most busy schools.

The program helps schools and teachers to better understand autism, and arrange their own school environment and systems to help some of these children get back to school. **Why is this policy needed**

Autism Spectrum Disorder (ASD) is a recognised health condition – a genetic problem located in the brain. It manifests in a range of developmental disabilities generally affecting communication, social interaction and behaviour, across a spectrum ranging from mild to severe. No two people with ASD are exactly alike. Many people with autism have co-morbidities, including epilepsy. Behavioural problems could be failure to develop peer relationships, lack of social or emotional reciprocity, hyperactivity, and maladaptive behaviours (head banging, pinching, hitting, biting, throwing objects, unacceptable noises, etc)

Over twenty years ago when deinstitutionalisation policies were adopted, the prevalence rates of autism were thought to be 1 in 10,000. Autism was thought to be a rare condition for which there was no cure.

Four years ago the Australian Autism Advisory Council published research that showed the prevalence rate in Australia was 1 in 160, but further recent research at Cambridge University finds the prevalence rate is more likely to be 1 in 64, and while autism is a lifelong condition, world-wide research clearly shows that with early intensive treatment, children with autism can 'recover' (their disability no longer impairs them from having a normal life; they are indistinguishable from their peers).

On this basis, the Australian Autism Advisory Council recently issued a *National Call to Action* calling for better access to diagnosis (“currently there is up to 24 months waiting list across States”); official reporting of autism spectrum disorders; early intervention for young children (0-6) where “every child has access to a minimum 20 hours of support per week” and a range educational services appropriate to need.

Ground-breaking research into autism shows that the gene itself is not damaged but instead the 'on-off' switch is impaired. In the area of acquired brain injury, research has shown that with constant repetitive work, the brain is able to regenerate. World-wide research has shown that this repetitive behavioural therapy (often called Applied Behavioural Analysis or ABA) can also benefit children with autism by "switching on" the brain.

ABA is a teaching technique which breaks down skills that children need to learn into very small discrete parts and teaches one step at a time. This applies to everything from tying a shoe to social skills, conversation and learning.

Because the brain's elasticity is at its greatest in the early years, a treatment program for children with autism must begin early for maximum benefit. It takes far less time and therefore costs significantly less.

### **After more than 11 years of Labor ...**

An autistic child can place enormous stress on a family. In some cases it can lead to family breakdown, or the abandonment of the child because of the exhaustion of parents and lack of access to support. A young adult with autism could find themselves homeless, or falling into a cycle of crime, juvenile justice and prison.

Parents seeking help face a demoralising round of meetings with a Government determined not to set precedents for desperate families that would have ramifications for their budgets. Too many children with autism are suspended or expelled at school for behaviours that stem from their disability (they are often undiagnosed); others are inappropriately enrolled in distance education. There was a seven-fold increase of students on the Severe Disability Register accessing distance education between 2006 and 2008. Often children with autism are denied assistance in schools because their IQ level is too high to qualify for a teachers' aide. In 2008, there were 85 children identified in Tasmanian State schools as having autism and 334 identified as having an intellectual disability.

The State Labor Government withdrew its support for the A-team pilot in the North and wants to reintegrate children back into schools despite evidence that many schools and teachers – and children – are not ready for this. Labor has said it will now review the program, but will not give a commitment to support this program into the long-term, nor its extension around the State.

Despite the Children Commissioner recommending to the Education Department that it provide evidence-based educational and behavioural intervention programs for autistic children for *at least* 20 hours per week over an extended period, the State Labor Government continues to refuse this level of support and, in 11 years, has only put in place a Statewide ASD Assessment team (TASDAS) to "*supplement generalist services available for children*". TASDAS is restricted to children under 7 years of age (for its first 12 months of operation), and referrals have to be accepted by paediatricians, a psychiatrist or a psychologist.

While T ASDAS has been only operating a short while, already there are lengthy waiting lists for assessment. Following an assessment, a report is given to schools, parents and others on *“management strategies, programming suggestions and recommendations to appropriate agencies/service providers”* however the reality is there is appropriate agency/service provider that delivers intensive treatment.

The State Government does provide limited access to children to speech therapists and psychologists through Childrens’ Therapy Services, and access to early learning services, but this is limited to two hours a week one-on-one support for children with autism.

The State Labor Government continues to argue that because every autistic child is different, so must the treatments. This is like saying a person with high blood pressure should be treated differently to the next, dependent on pressure levels. It has dismissed ABA as a treatment even though evidence throughout the world points to its success.

The Federal Government provides families with autistic children under the age of six years \$6000 each year for two years to be spent on intervention services, however apart from speech therapy, there are no such intervention services available in Tasmania. It also has established six new autism-specific child care centres, however on closer analysis these centres will be child care with 20 places reserved for autistic children and no treatment services. Aside from offering families some respite, the effect on the child will therefore be negligible.

According to the Australian Centre for Autism Services, the cost of a lifetime of care in supported accommodation is \$8 million. The Tasmanian Government currently spend \$63 million – nearly half the total disability budget - on supported accommodation, \$6 million on respite services, \$17 million on children in out-of-home care and \$10 million on the Ashley youth detention facility. It is fair to say many children and young adults with autism are supported in these facilities as a result of inadequate support offered to parents, and if we do not address early intervention treatment services, that expenditure has the potential to increase significantly.

In his report on children living in respite centres, Commissioner for Children, Paul Mason, said one outcome of lack of services and support for families of children with disabilities was that they *“soldier on until they crack and the need becomes a crisis. Government resources are expended largely on crisis-management instead of plan execution”*.

## FINANCIAL COSTINGS

	2009-10	2010-11	2011-12	2012-13
Total package for autism (excluding A-team, costed elsewhere)				

### **Internal only – costings:**

- No capital required – access empty DHHS buildings (St John’s Park) or school facilities (where a school has closed, or alternatively the early education centre in Campbell Street.

### Screening

- Costs of implementing and educating health professionals in the use of the tool – can be met within existing health resources.

### Diagnosis

- Costs will be offset by the current Assessment team – but would need to supplement this as the current team is inadequate to meet assessment needs. Cost ?????

### Centres

- Parents would spend some of the \$6000 (over 2 years) on treatment services, if they are eligible. We could insist on this to cut down costs of the centre. It is understood around 150 parents are receiving this at the moment.
  - Each Centre (only one costed in this policy) is 1 x psychologist per 20 kids as case manager (\$100,000) – Treasury costing for allied health professional is \$93,000 – and then we would tender for an ABA specialist to train therapists. Each therapist would get \$25 an hour (contract – current going rate). At 8 hours a day that’s \$1000 a week (say \$45,000 a year). 2 kids per therapist = 10 therapist needed at \$450,000. Total cost of centre could be \$500,000, but suggest recurrent costs are capped at \$1 million annum and we’ll try to get as many kids in that budget as we can. We could offset by those 20 kids getting Fed \$6000 assistance = \$60,000. Costs of training the therapists to be added in???
- Remember this is health economics – the cost of early intervention is conservatively \$50,000 a year – the cost of a kid for six months in respite centre is \$130,000.

### A-team

- Costed in education policy.

### **Benefits of this policy:**

- If we don’t act we will have a crisis of care on our hands and all the costs that entails.
- It is believed Tasmania would be the first State Government to put in place early intensive therapy services for children with autism.