

**ATAC**

**Action for Tasmanian Autistic Children**

The Premier  
Paul Lennon  
Parliament House  
Hobart

9 April 2008

**RE: AT RISK CHILDREN IN TASMANIA**

Dear Premier

A representative meeting of families with children with Autistic Spectrum Disorder [ASD] held last Thursday 27 March 2008 welcomed your interest in the problems of families with at risk children.

There is little doubt that autistic children fall into this category. It is estimated that 85% of these children during their lifetime will be abused either physically, mentally or sexually. I am myself grandfather to two autistic boys who are in this category.

At present there are two coronial enquiries into the death in Tasmania of young men with Autistic Spectrum Disorder. Autistic children are regularly breaking down under the pressure of schooling. We still have children leaving school incontinent, unable to talk, and unable to read and write. If these children were included in literacy testing, Tasmania's dismal record in this area would sink further.

Mr Premier, one of our greatest problems is that autism and other intellectual disabilities encompass so many separate Government Departments, viz Disability Services, Child and Family Services, Education. When a family is in trouble all these departments fight to keep the cost of helping them within the compass of another department's budget. This ends up with families who are under enormous pressure abandoning their children in hospitals, respite centres or at the offices of one or the other of the services.

Mr Premier, it is now ten years since de-institutionalisation took place in this State, yet for children with ASD little has changed. Most still end up in care, in group homes, or in Ashley Youth Centre and later in Risdon itself. For it is no co-incidence that in the ten years since the closure of Royal Derwent Hospital and Willow Court that the numbers in detention in Tasmania have risen by 70%.

The cost of this neglect is enormous for the State. The lowest amount we pay to group homes is \$70 thousand per annum. If someone enters a home in their twenties and lives till they are in their 80s, the cost to the Government is in the millions of dollars.

We have known since the 70s, when Professor Lovaas began working with autistic children at U.C.L.A. in the USA, that programmes can be put into place that greatly benefit autistic children. Lovaas' research showed that nearly 50% of children in these programmes would reach a stage where they no longer showed up as autistic when tested, and most of the rest would improve enough to remain living within the community. Only a small percentage would not benefit.

Mr Premier today, over 30 years after Lovaas' research was first published, his methods have been refined and improved. Now we have programmes such as the Greenleaves Programme in Northern Ireland using ABA to teach life skills to the worst cases of autism. They do not aim to do more than train these children in those life skills that will allow them to live in their homes and not be institutionalised.

In November 2007, *The Foundation for People with Learning Difficulties* in the UK issued a report called "The Economic Consequences of Autism in the UK". This report shows the following:

- The aggregate cost of supporting those with ASDs in the UK is £27.5 billion annually.
- The lifetime cost for maintaining someone with an ASD and a learning difficulty is estimated to be £4.7 million, and £2.9 million for someone with a high functioning ASD.  
[All figures are pound Sterling at 05/06 value']

The report then details costs for those with high-functioning ASDs and those with low-functioning ASDs using the IQ level of 70 to differentiate between them. It goes on to detail costs for people with ASDs in the age brackets 0-3, 4-11, 12-17, and finally 18 and over.

At each age level the costs rise. For those who have low-functioning ASDs, of the £4,683,240 cost of care for a life-time, only £420,000 is spent to the age of 18, and £4,261,920 is spent after age 18.

Similarly, for those who have high-functioning ASDs, of the £2,941,376 life-time cost of care, only £300,000 is spent to age 18, with £2,641,260 spent after age 18.

It is the imperative to drive down the costs in the years after 18 that has seen advanced countries such as the USA, Canada, and now the UK and Europe, adopting Early Intervention Programmes. Mr Premier, this approach will only work if the Early Intervention Programmes themselves work, and are able to keep children with ASDs out of institutions when they become adults. This is where the pressure for evidence-based programmes, and in particular ABA programmes is coming from.

Why Early Intervention programmes? If a child is reaching normal childhood development at a rate slower than the normal rate of development, the earlier a programme is commenced to rectify the delay, the easier the task becomes. For instance, if a child is developing at half the normal rate, by age two that child will be one year behind the norm, by age 8 he will be four years behind. To overcome this deficit a programme must be intense enough for the child to achieve the normal rate of progress, and must as well eat into the deficit so that progress towards normal development is made.

Let us contrast the approach in Tasmania, where each government department denies the responsibility for people with ASDs and does as little as possible, passing on responsibility to another department, with the opposite approach adopted in many US states.

To begin with let us look at diagnosis, which would lie under the umbrella of the Department of Health and Human Services. If there is a serious attempt to come to grips with the problem of autism, then every attempt would be made to ensure that diagnosis is made as early as possible, and children be given Early Intensive Intervention as quickly as possible. If, however, there is an intention to do as little as possible and push the cost onto the next government department [Education] then there is no real emphasis on diagnosis.

In Tasmania we have no inter-disciplinary bodies to specifically deal with diagnosis of ASDs. General facilities such as Calvary Re-hab and Clare House are the closest we have. Diagnoses such as Developmental Delay or Global Delay are still prevalent. Most GPs and even many paediatricians and psychologists are not familiar with the disorder. With few services available there is nowhere for the child to be referred anyway.

The Education Department provides a generic Early Learning Service with programmes for disabled children. This began with 5 hours per week, but now families are fighting to get 2 to 3 hours a week.

The Commonwealth Government recommendations for Early Learning Programmes for children with ASDs is for a minimum of 20 hours per week. In 2005 generic programmes based on eclectic methods similar to those used in Tasmania were tested by Jane S Howard et al of California State University. The programmes tested in this research were an average 15 hours per week. It was found that only 2 autistic children had any gain at all, and this was in the motor skills area where original testing had shown no problems existed. There were no gains in any other areas, and indeed two children had regressed. It can be seen that if 15 hours of eclectic programmes did not help autistic children, even 5 hours a week, rather than the 2 to 3 now given in Tasmania, will produce regression.

How is this being handled in the USA? Many State Governors have appointed Autism Commissions to advise both them and State Legislatures on autism and related disorders. These Commissions have made recommendations that have been brought into law, or they are about to be.

For instance, the Californian Commission has recommended 7 items for action in 2008. The major recommendations include the following. Firstly, for a law to make it mandatory that all paediatricians screen for autism on the first 'well consult' with a child so that all children are screened at least by 18 months to 2 years. The second recommendation is for a law to make it mandatory for Health Insurance to provide for evidence-based early intervention programmes for children with autism.

The proposal is for those children whom the paediatricians believe may have ASD to go before a multi-disciplinary panel for full diagnosis. The Best Practice Guidelines for Diagnosis emphasise that diagnosis must be seen as a process leading to treatment programmes. They stress that developmental delay/global delay is a symptom and not a diagnosis. If delay is detected, further testing must take place as the delay may have many causes - Fragile X, Epilepsy, Rhetts Syndrome, ASD etc.

Let us now move on to the school years. When an autistic child commences at school, there are no programmes to teach that child. A five year old with a developmental delay of three years is expected to cope in a classroom geared for children with normal development. If they are high-functioning there are no programmes to cater for their social deficits. The very severely affected - the incontinent or those with language difficulties - may qualify for an aide. However, the aide works to the direction of the classroom teacher, and is regarded as an aide for the class, not for the child. The aides themselves have no specific training in working with children with ASD. This continues throughout school life, with some children still incontinent and without speech when they leave school. The stress of school for all these children causes them to become disruptive and destructive, and many become truants.

This situation contrasts with the situation in the USA. There the Federal Government passed an Act, the Intellectually Disabled Education Act (IDEA). If States want Federal Funding they must accept the terms of this Act. One of the clauses of this act provides for FAPE (Free Appropriate Public Education). Under this section, a school must provide to parents an I.E.P. (Individual Education Programme) each year. The I.E.P must contain proposals and details of programmes to be used to educate the child. If the parents are dissatisfied and cannot reach agreement with the school, then the parent can refer the matter to an Independent Tribunal for adjudication.

The tribunals require evidence-based programmes to be adopted. Many tribunals have ruled that the only adequate evidence-based programmes are those based on Applied Behavioural Analysis. (ABA) If the schools are unable or unwilling to provide these programmes, the tribunals will award the cost of a home-based ABA programme to the parents. This use of IDEA and FAPE is forcing evidence-based programmes into State after State.

This movement is becoming world wide. It is driven by the economics of the care of autistic children. Simply put, 3 years of ABA costs the same as one year's cost for a group home or institution. As most autistic adults live well into their 70s, the short-sightedness of present policies is costing our State dearly. It is inevitable that change will take place, and the only question is whether Tasmania is a leader in this change, or at great cost to the taxpayer, becomes a late follower.

Mr Premier, **ATAC** believes that the various government departments involved with children with ASDs are capable of only looking at the aspects of autism that they deal with, and that at every level they protect their own budgets and are unable to see the total picture. For instance, the Education Department sees no value in spending money in the area of autism when the benefits of a new approach will accrue to the Health Department in less cost for group and residential home care. We believe that as in the USA, where State Governors have embraced change, then in Tasmania, you, as Premier, have the overall benefit of the State and its people as your focus, and that you are therefore the person most suited to drive the necessary changes across the Departments concerned.

We believe that now is the ideal time for change to occur. As you will be aware, the Federal Government has promised to set up an Early Intervention Centre for Autism for 20 children with ASD in Devonport. This centre is to be based on THE LIZARD CENTRE in Sydney and the AEIOU centre in Brisbane, both ABA centres. They have also promised money for training and for families to help with the cost of Early Intervention

Programmes in the home.

My organisation is concerned that this Federal money may well be wasted in Tasmania as no infrastructure exists here. We believe that a commitment to change and to develop the necessary infrastructure from your Government could substantially reduce the costs to the State. We also believe that your influence with the Federal Minister, Bill Shorten, could be very valuable.

I have been instructed by my members to seek discussions with you. We believe that this is urgently required as the Federal money could end up doing nothing for autistic children in this State.

Yours

RJ Law

Secretary **ATAC** (Action for Tasmanian Autistic Children)

ph - 03 6286 1316

email - [atactas@gmail.com](mailto:atactas@gmail.com), [jerobi40@bigpond.com](mailto:jerobi40@bigpond.com)

website - <http://www.atacc.biz/atac>,

<http://www.melbarant.com/atac>

PS: On March 29 2008, Morris lemma, Premier of NSW, announced that his Government will build Earl Intervention Centres for children with Autism, commencing with a \$1.2 million centre in Western Sydney.