

Sunday, 25 May 2008

TO BILL SHORTEN  
FROM ROGER LAW, Secretary ATAC - Action for Tasmanian Autistic Children

**RE: NEEDS OF CHILDREN WITH ASDs IN TASMANIA**

Dear Bill

My organisation was very appreciative of the positive meeting we had with you in Hobart on May 7 2008. I have been directed to provide you with further details of the type of programmes we see as necessary for this State, and to outline to you the difficulties here, and the ways in which we believe these can be overcome.

**EARLY INTENSIVE LEARNING CENTRE**

**ATAC** supports this proposal and believes that there should be one in each region of the State. Our support is predicated on our understanding that these centres will be based on the principles of Applied Behavioural Analysis. (A.B.A.)

We have concerns about the costs to families of the services provided. We are aware that many of the families dealing with ASDs are single parent families with one or two children with ASD. Unable to work because of the difficulties of looking after their children, they survive on a Carer's Allowance or on the sole parent's payment. The extra costs associated with raising an autistic children have caused many already to be deeply in debt. While the Centre may allow them to seek employment, if there

is a charge for their child to attend, then employment may not be economically viable for them, and so the Centre itself may not be viable for them also..

## **EARLY DIAGNOSIS AND SCREENING**

As we explained at our meeting, the problems of diagnosis in this State are overwhelming for parents. We suggested that the Child Health Care nurses in the Child Health Clinics could do early screening at 18 months and 24 months, using the Modified Checklist for Autism in Toddlers (M-CHAT). I attach a copy of this checklist, and information about this screening tool.<sup>1</sup>

As not all parents take their children to these clinics, I suggest that the A.M.A. be asked to co-operate and have their GPs and Paediatricians do this screening as well.

## **DIAGNOSIS**

We are aware of the State Government's proposal for (a) Diagnostic Panel/s for diagnosis of Autism in this State. While we agree with the concept, we are concerned that the bringing together of a group of people who have previously proved unable to diagnose will only compound the problems we already face.

To prevent this happening, we suggest that Best Practice Guidelines for Diagnosis and Assessment be adopted for the panel. I attach a copy of the Guidelines produced by the California Department of Developmental Services. These guidelines are the most comprehensived that our research has be able to find, and we suggest their use in Australia would vastly improve diagnosis in the country.

The integration of the panels with the Early Interventions Centre is a must. You will see that in our proposal for the Centre we have advocated advertising Australia-wide for experienced autism practitioners to staff the Centre. This is most important in

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<sup>1</sup> Refer to appendix attachments one and two for the email accompanying this letter.

the case of the Programme Director, who must be qualified and experienced in Diagnosis and in the drawing up of programmes. Of necessity, this person should also be head of the Diagnostic Panel.

## **EDUCATION**

It is obvious to **ATAC** that considerable training is going to be necessary for screening and diagnosis to be successful in Tasmania. The Child Health Nurses will need training on the use of the M-CHAT screening tool. There will be need for participants on the Diagnostic Panels to have extensive training to be able to work at a level required by the Best Practice Guidelines<sup>2</sup>. Some of the co-morbidity tests recommended may not be available in this State, and may need to be provided here or interstate.

**ATAC** believes that the money for education in Tasmania would be better spent in this type of training (specific and targeted to the State's needs) than upon another 'fly-in' round of lectures for teachers and parents that are non-specific and do not leave any professionally equipped practitioners in the area of autism.

## **NEED FOR OUTREACH SERVICES**

Because of the total lack of any attempt to educate autistic children in the Tasmanian Education system, we have many children who have received no services and are failing their schooling. These children need to be reached by outreach services which largely could be conducted in withdrawal rooms in the school. In the worst cases, where children have broken down under the stress of the school environment, outreach services should be located in their own home.

As Tasmania is a very decentralised State, many affected children will live outside the catchment area of these centres. For instance, our organisation is aware of

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<sup>2</sup> Refer attachment 2 sent with the accompanying email

clusters in at least two areas of the East Coast. Areas such as these need to be identified and outreach services provided in the local schools or at home.

## **PARENTAL EDUCATION**

Once again, **ATAC** is sceptical of generalist 'fly-in' lectures. We believe that specific education should be provided to parents at the Early Education Centres. Any programme for the child with ASD must be consistent with the work being done at the Centre also being backed up in the home. This will only happen if training is provided in the Centre,

## **TRANSITIONS**

When the Case Manager believes a child is ready for school, there should be a meeting between the Centre, the parents and the school. At the meeting plans should be made for the gradual transition of the child to school, If an aide is to be provided by the school, then training for the aide can be provided. An Individual Education Plan (IEP) can be agreed to and signed off on.

The IEP will cover the first twelve months of schooling. It will clearly record the skills of the child at that time, and will clearly list the score, and the name of the test used in all critical areas of educational development. It will detail the levels to be achieved, and the measuring test to be used to check that the goals are being achieved. No unattainable goals and no aspirational statements, should be included.

It will then be possible to test the child every 6months to check that expected progress is being achieved. If it is not, then the outreach services from the Centre can be used to get things back on track and further train school staff. A new IEP must be done at the completion of each school year.

This proposal is designed to be flexible in implementation. Last year there were

6,500 births in Tasmania. One the present Australian statistics, one in 160 of these children will have ASD. This gives us a ball park figure of approximately 40 autistic children. If we assume that with early screening and proper diagnosis that this may increase to one in 100 children, we are looking at 65 children who will need early intervention in two years time. If we then assume there is equal distribution across the State (which there will not be), then we require in Hobart a Centre that can handle an annual intake of 20 to 33 children, in Launceston an annual intake of 10 to 16, and the same in the North-West of the State.

The flexibility of this proposal would allow for one Centre in the North-West, with 2 campuses, one located in Burnie and one in Devonport. There would need to be outreach services for the West Coast and other remote areas if there are children diagnosed in these areas. This may allow for two small centres capable of handling 6 children each with a large outreach capacity. Outreach would decrease as the number of children who had not had an early intervention programme will likewise decrease once the Centres are operating.

Similarly, in Hobart two Centres could be required one each side of the Derwent, with that located on the Eastern Shore providing outreach to the East Coast, and the Western Shore providing outreach to the South Huon etc and the Derwent Valley. **ATAC** believes that with the co-operation of the State Government premises are available to quickly implement this proposal.

We are concerned that if the responsibility for a Centre is handed over to the State Education Department and their present personnel, then nothing will change. At present there is no-one in their employ who is qualified or trained to draw up full programmes for children with Autism Spectrum Disorders.

**ATAC** is ready to co-operate with you in developing programmes and interventions for children with ASDs in Tasmania. If there is co-operation now between State and Federal Governments we believe a great deal can be achieved quite quickly for one of the most needy groups in the State.

Yours fraternally

Roger Law

Sec **ATAC**