

Dear member

A story about autism/ASD aired on ABC Stateline Canberra on Friday, December 4, 2009. The ACT Government disputes what Ms Blakemore said in the interview. Some members of the ASD community accept the Government's criticism of Ms Blakemore's interview.

The ACT Government insisted on having their response attached to the ABC's online transcript.

Please view the video at the ABC Stateline webpage

<http://www.abc.net.au/news/video/2009/12/04/2762759.htm> or read the transcript.

Following is some background information.

Following Ms Blakemore's previous Stateline story (14/8/09, see

<http://www.abc.net.au/stateline/act/content/2006/s2657680.htm>) we sought meetings with politicians from all parties in the Assembly including 3 relevant Ministers.

- Our request for a meeting with Mr Barr MLA was declined.
- Ms Gallagher MLA declined to meet following the Stateline story. She (or her office) subsequently cancelled a meeting that was scheduled for November. After our requests that the meeting be reinstated, she agreed to meet in Jan 2010.
- Mr Hargreaves MLA met us ... however he said he had little authority or decision making powers, so he isn't really a full member of the Government. Ms Burch MLA, the ACT's new Minister for Disability and Community Services, has yet to schedule a meeting with Autism Asperger ACT.

In the Stateline story, Ms Blakemore said

"... after the last Stateline story aired, we met with the Liberals, we met with the Greens, but the current government weren't prepared to meet with Autism Asperger ACT."

The Government's response says ...

"There has been no unwillingness on the part of the Government to meet with members of Autism Aspergers ACT and in fact the Government has met with representatives of the organisation on several occasions."

Ms Blakemore did not suggest "unwillingness" on the part of Government ... she said members of the Government "weren't prepared to meet": she describes what happened to requests for meetings with the Government between the Stateline story in August and the time the interview was recorded. Clearly from its own account of events, the ACT government did not meet and discuss the lack of services in the ACT before Ms Blakemore packed up and moved her family to England.

Previous meetings between the Government and representatives of the association, and possible future meetings, have no bearing on the facts of this matter. And the lack of meetings Ministers over the 4 month period (August to December 2009), despite requests to meet, does not indicate preparedness or willingness to meet.

There is no basis for saying Ms Blakemore was inaccurate over the preparedness of the ACT Government to meet in the period between the Stateline story in August and her interview for the December story.

In the Stateline story, Ms Blakemore said

"... they haven't increased funding, they've decreased funding, they've decreased services whilst the autism rates have been increasing."

She found that Therapy ACT did not backfill the position or the services for their clients when the staff in Therapy ACT, who were meant to provide services for her son, left or were absent for a time. This means that funding and services for her son decreased ... as Ms Blakemore says.

The Government responded ...

“The Government rejects accusations that funding has been reduced and in fact in the 2009-10 Budget the Government provided \$5.8 million over four years to increase services provided by Therapy ACT. This includes additional speech pathology services and therapy positions to provide early intervention play based programs. The funding will also enable the Therapy ACT autism team to double in size from February 2010 to 12 staff. The team will also expand its role from assessment and family support to include intervention services for children up to the age of 12.”

This is spin. Ms Blakemore did not discuss funds “to increase services provided by Therapy ACT”. Nor does the existence of such funding ensure funds and services for children with ASD do not decrease. Such a decrease can occur for several reasons.

- Therapy ACT provides services for a range of clients so an increase in its services says little or nothing about funding and services for children with ASD.
- Changing numbers of children receiving services means that changes in total services do not relate to the services children with ASD receive.
- Service may not be evenly or consistently provided for disability groups or individual children: some groups may get service and ASD may get less.
- Fewer than half the children with ASD are clients of Therapy ACT.

Funding and services on a per child basis could remain the same if funding and services kept pace with the number of children diagnosed with ASD. Both nationally and in the ACT, the number of children diagnosed with ASD has more than doubled in the last five years ... as it has for the preceding three or 4 five year periods. There is no sign that funds and services for children with ASD doubled in 5 years.

The funds mentioned above appear to funds to increase services above the service level provided in the base funding. This mechanism lets the Government say it increased funds while it decreases funds and services relative to the level of funds and services provided in previous years.

There are two adjacent commitments in the 2009-10 Budget for \$3.5 million and \$2.3 million respectively. Together, these add up to \$5.8 million. These items may be what the Government is referring to.

<p>Addressing Speech Pathology Waiting Lists \$3.5 million over 4 years</p>	<p>Provides additional speech pathologists at Therapy ACT for young children with high priority needs.</p>
<p>Play Therapy Services for Young Children \$2.3 million over 4 years</p>	<p>Provides specialist intervention services for young children diagnosed with Autism Spectrum Disorder (ASD) and other disabilities.</p>

The Budget Speech says

“\$2.28 million in funding will be provided for Play Therapy Services for children with a disability, fulfilling a key election commitment. \$3.5 million over four years will provide 8 additional speech pathologists and services for young children with high priority needs; meeting another election commitment and addressing a key area of concern within the ACT community for parents of young children with speech disorders.”

The Speech Therapy item (\$3.5 million) is for “young children with speech disorders”, not for children with ASD (unless they also have a speech impediment?). News reports say speech therapy waiting lists were around 650 in Nov 2008. Therapy ACT had around 206 people with ASD aged 0-17 on their books ... so this Speech Therapy item is targeted mostly to children with other disabilities, not for children with ASD.

The ACT Government has a track record of saying money was allocated for children with ASD but not really delivering a service for children with ASD. The ACT Government develops its budget initiatives without discussing them with the ASD community, then it adds ASD as an afterthought. The methods can be to ...

- budget for services for children with autism/ASD that cannot be staffed at the level indicated then use the funds in other programs;
- tack on the phrase “including autism” after “children with a disability”;
- say the service is “for children with autism and other disabilities”, when it is really for children with other disabilities; or
- claim services for children with speech disorders are for children with autism.

The Government did not discuss increasing speech therapy with Autism Asperger ACT. Our peak body had no input into the implementation plan or the recruiting process. Most children with ASD need more speech therapy than is funded by either level of Government. The professionals who work in the ACT Government’s therapy services do not provide services that families can access via the Commonwealth Government’s HCWA package. To use both sets of funding, families need to see two or more therapists ... a practice frowned on by the professional body for speech therapists. Getting advice from multiple sources means families get duplicated or conflicting advice. It is confusing and inefficient, and having relationships with extra therapists complicates family life.

Families would prefer that they can use funding from both Territory and Commonwealth Governments (and those who can afford to make their own funding contributions) through a single therapy service. They want access to therapists and allied health professionals who are trained and experienced at providing programs for children that meet best practice guidelines that they recognise. The staff Therapy ACT recruits are not trained and experienced in supervising programs for children with ASD that are “best practice”; that is individualised, intensive, 20+ hours per week for two or more years and ASD-specific programs.

The Budget Speech indicates that the Play Therapy item (\$2.28 million) is “for children with a disability”, not just for children with ASD.

Play Therapy for children with ASD is contentious. As we have seen before, Play Therapy helps children with autism **who do not have severe autism** ... so this \$2.28 million is for the 13% of children who are least disabled by their ASD. Nor is there any evidence of demand for play therapy for children with ASD beyond that already provided as part of the playgroup element of the Commonwealth Government's Helping Children with Autism package. This is money for an ill-advised election commitment ... it is not money to help most children with ASD.

The ACT budget says nothing about "Therapy ACT autism team to double in size". Google finds nothing either. Nor has there been any discussion with the association. Is this policy on the run?

The ACT Government does not know how much money it spends providing therapy services for children with ASD. It does not know whether it spends more or less each year. It does not know how much it spends per child. Since it does not know, it cannot reject "accusations that funding has been reduced". It makes the claim and hoping no one refutes it.

On the numbers, funding reduced in 2008 and 2009 relative to the previous year. In 2007, funding related to ASD was \$986,000, then in 2008 at least \$657,000. The Budget allocation in 2009 for Play Therapy as an election commitment is just \$461,000 which may be less than Budget allocations in previous years (how much of it really went to ASD is unknown). The 2004 Budget provided funds "... to expand Therapy ACT’s autism assessment and support services" at the rate of \$445,000 in 2007. The 2005 Budget provides funds "to develop a new service to assist families who have children with intensive support needs, particularly those with challenging behaviours such as autism" and for

"Additional Therapy Support for Children with High and Complex Needs (Including Autism)" at the rate of \$541,000 in 2007 and \$657,000 in 2008.

I call on the detractors to withdraw their criticisms of Ms Blakemore or produce actual evidence of intended inaccuracy. I believe the information above shows Ms Blakemore's interview was accurate. I am disappointed that the Government and some members of the ASD community said she was inaccurate.

regards

Bob Buckley

14/12/2009