A4 Autism Aspergers Advocacy Australia

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* SPECIAL EDITION *

Australia's first national Autism Forum

Bob Buckley

Christopher Pyne MP, Parliamentary Secretary for Health and Ageing, held the First National Autism Forum at Parliament House on 15 June 2005.

A4 wrote to Tony Abbott MP, Health Minister, in May 2004. Mr Don Randall MP asked Minister Abbott to meet us. A date was set in February 2005. Senator Humphries came with us to the meeting. The Minister agreed to hold a "stakeholder conference" (see his email, published in A4 Update 2005 #3 (March)). A member of the Minister's office staff was given responsibility for organising the conference.

There was no sign of progress on the conference until people who live in Mr Abbott's electorate, some members of Learning to Learn and the Brockhoffs, wrote to Mr Abbott MP asking about the progress of the "stakeholder conference". The Minister passed responsibility for organising the conference to his Parliamentary Secretary, Mr Christopher Pyne MP. Mr Pyne MP, encouraged by Mr Tony Smith MP, had staff from his office and the Health Department organise the forum.

The day of the forum started with a working breakfast. Parliamentarians showed overwhelming interest in the forum with the result that some latecomers missed out due to the size of the venue.

All national ASD groups (both A4 and ACA), state Autism Associations and ASpect Australia Pty Ltd attended the forum. Mick Clark (President) and Verity Bottroff (Professional Committee Chair) represented ACA. Wendy Lawson's presence and contributions were extremely valuable. The organisers asked Prof Margot Prior but did not invite other relevant academics or professionals initially; and by the time they were asked only Diane Bailey-Tribe could attend.

The federal Health Department invited state Health Departments to attend. But they didn't. Not a one … not even the ACT Health Department who were already in town or NSW Health with representative just across the border. State health departments, who are charged with total responsibility for the health of children in their state, refused the call to come to Canberra to discuss the clinical needs of young children who are diagnosed with a clinical disorder.

Mr Pyne MP opened the forum proper announcing a $50,000 grant for autism research. Clearly, Mr Pyne MP is keen to make a significant difference for children with autism. Note that Mr Pyne MP was also the Parliamentary Secretary involved in simplifying Carer's Allowance in relation to Asperger's Syndrome.

The clear message from government is that the ASD community must give government a united and simple message about what needs to be done. Government is a political process. It is up to the community to motivate government to act.

Prof. Margot Prior's gave the keynote address, a thorough presentation of ASD-related material. While the material presented was quite familiar to the representatives from the ASD community, a good introduction to autism and ASD may have helped bureaucrats attending the forum, the authorities who are responsible for services but do not specialise in ASD.

Prof Prior told the forum ASD affects just 1 in 1000.[1] This would mean currently, at least five out of each six ASD diagnoses in Australia are wrong.

The morning session concentrated on identifying challenges. The main focus was on issues relating to children aged 0—5 years, the pre-school years. The "key issues" identified were:

- Improve access to diagnosis and assessment (no waiting lists, multidisciplinary)
- Develop nationally recognised diagnosis benchmark process
- Build skilled workforce
    - Recruit, train, retain
    - Better management and reward
- Develop agreed national … either service level standards for autism, or outcome measures (use international reference points)
- Develop/expand continuum of services at life stages
- Develop access to appropriate and early intervention and treatment (including prediagnosis)
- Need whole of system perspective and response
- How do we get this agenda as a compelling agenda … make the case?

The afternoon session started with a summary of services in WA. The focus was to discuss solutions to the challenges. The "proposed strategies" were:

1. Recognise ASD as a discrete disorder and specific needs
2. Develop and articulate clear pathways
3. Targeted rebates/coverage order/Medicare/health insurance
4. Project recurrent funding for national 'clearing house'/secretariat – info. exchange
5. Funding for IT/laptops for each child ($44 million)
6. National register of autism
7. Early intervention
8. Post-school
9. Adults — coordinated support across …
10. Service brokerage
11. Nominate a responsible Minister and Department to take responsibility

There was widespread agreement about the challenges and the nature of solutions. While state representatives presented existing services in the best possible light, there was widespread consensus that currently, substantial improvements in services and outcomes are urgently needed.

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[1] In a subsequent short email exchange Prof. Prior wrote "I have some problems with the methodology and the estimates from the Australian studies and believe that we do need a well conducted study to get better estimates. None of the Australian sampling so far would meet international standards". Australian data includes two population studies (ACT and WA that do not involve sampling) and the ABS surveys generally meet international standards.

The message from the ASD community to the forum about the needs of young people was consistent. People with autism and their families spoke convincingly, with great passion and authority.

As you can see, the recommendations were still in a relatively primitive state at the end of the forum. The facilitator is preparing a report. That will take about two weeks. The official version should be given to government shortly.

Convenor's Message

Dear A4 member

This Update aims to provide some information about the political processes and systemic advocacy that A4 is doing. This activity is done on behalf of A4's members, so I sincerely hope we are telling the government what it is that you want.

The big news is that Christopher Pyne MP's, Parliamentary Secretary to the Minister for Health and Ageing, held the government's first nation autism forum.

The forum went very well. The forum increased awareness of ASD in the federal government among politicians and a few federal health bureaucrats. The forum showed state governments that ASD is now a federal issue.

The ASD community, and A4 in particular, were very well represented. A4's representatives were Wendy Keifel (Vic), Jenny Couper (SA), Dale Daniels (NSW) and myself (ACT). Meredith Ward (Vic) represented AFSA and A4.

I was extremely disappointed that the states and territories failed to send a single representative from their health departments. They were all invited to attend a forum where the focus was autism/ASD in the early years, before children enter education yet their clinical diagnosis shows they need clinical attention. Only WA sent a relevant representative. The WA Disability Commission representative told the forum how the WA government takes responsibility for addressing some of the clinical needs of young children with autism/ASD.

More about the forum can be found in the articles (see above and below).

We, the ASD community, have to develop constructive relationships with governments. Hopefully, the forum will become the beginning of, the first step towards, better outcomes in health, education, employment, independent living and community participation for people with ASD.

Government has a perception that the ASD community is divided on what needs to be done. Government will use this an its excuse for inaction for as long as it can.

The ASD community has to defeat the government's perception and overcome this barrier to progress. The forum showed that the ASD community, being ASD organisations from around the country, has discernible unity of view.

Many in the academic and professional community however lack this shared vision. Currently if you ask 10 academics and professionals what is needed for ASD, you'll get at least 23 different views ☺. Some senior health professionals, who have little knowledge of and no actual experience in treating autism, tell politicians that early intervention for autism is a waste of money (based on what they were taught in their training decades ago by people who also had no experience in treating autism).

In relation to ASD, many health professionals have squandered the trust and respect people give them initially. For example, a significant number of children with ASD experience gut problems (as do all children). A normal response to gut issues for a child who has ASD and a repertoire of autistic behaviour is to the increase autistic behaviour. When the gut issue is addressed successfully, the child reduces its autistic behaviour. Health professionals who deny or refute parent observations like these lose trust and respect.

On the academic side, the NHMRC and ARC records show just how little research into autism has been done in this country (more on this subject in the next edition) ... and by whom. This reflects the level of expertise available to the community.

Academic and professionals are in disarray over ASD. Their squabbles (both local and international) impede progress towards better outcomes. Many of them talk about things they know nothing about. For example, many of them say "effective early intervention is expensive"[2] yet none of them has a cost model or any cost comparison with the alternatives. Nor do they have the expertise to develop, or even critique, a cost model. Real professionals do not give advice on subjects that lie outside their area(s) of expertise.

Currently, the focus is on answering the question "What is the best way to provide an inadequate service?" All answers to this question are of no value.

Bob Buckley, Convenor
27 June 2005

Personal commentary on forum notes

Bob Buckley

The forum facilitator wrote the summary notes and is preparing the report to Christopher Pyne MP.

The forum covered a lot of ground in a short time. Some of those present have discussed the issues for years. Others, like me, are relative newcomers.

Many readers (A4 members) have not had the chance to consider many of the issues raised. Here are some personal thoughts on the "issues" that the forum identified.

1. Develop access to appropriate and early intervention and treatment (including prediagnosis)
   The lack of effective early intervention is the most critical issue for pre-school age children with ASD. This is a crucial services gap.
   Children with ASD need to be taught learning skills. They need to be taught receptive and expressive language, how to attend to a teacher, how to imitate the teacher and other children. These are prerequisite skills for group learning ... and children with autism do not learn these skills in a group setting; though they have to learn when to apply them while they are in a group setting.
   Children with ASD need to be taught social skills. They often need to be taught to observe their peers and to try do as others do. Many of them need to practice theory of mind tasks. They often need to be taught how to interpret parts of the world. For example, that we use 2D pictures to represent 3D objects.

2. Improve access to diagnosis and assessment (no waiting lists, multidisciplinary)
   This seems to mean earlier diagnosis. The purpose of this should be to ensure immediate access to early intervention, hopefully resulting in better outcomes. However, a diagnosis does not give access to appropriate early intervention unless families can access or provide treatment independently.
   Early diagnosis reduces uncertainty and the associated stress for parents. This is a good but not compelling reason.
   The available data, according to my analysis, shows diagnosis rates in Australia are similar to USA and the UK. This is a sign that we now seem to be identifying the children who need services. While they may not get services, we know they need them.
   Personally, I regard ongoing monitoring and program development as more of an issue than whether diagnosis is done by a multi- or trans-disciplinary team. Initial assessment, were it done thoroughly, might identify priority program elements and set a baseline for measuring program effectiveness.

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[2] Some of them insert "extremely" or "incredibly" before "expensive".

My reading of the research results leads me to believe initial assessment is a poor predictor of outcomes. Parents should be very wary of anyone suggesting otherwise.

3. Develop nationally recognised diagnosis benchmark process
   See above …

4. Develop agreed national … either service level standards for autism, or outcome measures (use international reference points)
   The forum discussed developing service standards for people with ASD.
   I feel it would be better to measure outcomes for people with ASD. For pre-school age children, the measures would include things like:
   - improvement in communication and social skill levels as measured by standardised tests;
   - Proportion of children with ASD who are toilet trained on entering school;
   - Rankings for attending to the teacher, imitates peers, plays with peers, etc.
     I suggest measuring outcomes for people with ASD is better than a service standard because it can foster continuous improvement through competition between service providers rather than setting a minimum for services. Besides, FaCS already has a National Disability Service Standard that is unenforceable and mostly unknown or ignored.

5. Build skilled workforce
   - Recruit, train, retain
   - Better management and reward
     Australia lacks skilled staff at all levels. For example, Therapy ACT cut therapy services in its 2005-06 budget claiming it cannot recruit staff. Most service managers do not know what skills their staff needs.
     Training for allied health professionals does not adequately address ASD-specific methods.
     Staff supporting children in school and in care are not given the training they need. There is no career path. They work under bad management practices.

6. Need whole of system perspective and response

7. Develop/expand continuum of services at all life stages
   From my perspective, these two issues are related. We need a model that makes the person with ASD at its centre provides an integrated service suited to that person and their associates. Such a service could offer early intervention or treatment at a time and place that provides respite for carers. It would extend the child's early intervention program into childcare and/or pre-school settings; and into the home.
   An effective model would recognise that a young child with ASD may not be ready for "school", and would use the resources normally used in an education setting to deliver essential clinical intervention to develop learning skills including key communication and social skills. When a child is ready, he/she would progress smoothly, decreasing clinical and increasing education emphasis in the child's program.
   The model would ensure schools prepare for and are ready for a child with ASD; rather than the existing practice of dumping the child into each new setting … where it typically takes at least six months before things start to settle.
   Stove-pipe organisations and service abysses were much mentioned.
   Governments talk about customer-, client-, family- or person-centred service provision. But it is all talk and no substance. In the absence of good management and skilled staff (see above), these terms belong in bureaucracy's dictionary of semantically null terminology, spin and impossible dogma.
   The strategies proposed at the forum follow. The forum included state and federal government representatives from all jurisdictions, relevant professionals and the autism community. There was broad agreement to these items. I've added some commentary.

- Recognise ASD as a discrete disorder with specific needs
  Previously, A4 asked government to recognise ASD as a discrete disorder and to report it separately, especially from mental retardation or intellectual disability. A few government agencies sometimes separate outcomes for people with autism/ASD in their reports. But there is a long way to go.
  The call to recognise ASD as a discrete disorder now comes from the whole ASD community and from state and federal government representatives.
  Recognition means separate reporting. Reporting separately on ASD should show where outcomes in health, education, employment, community participation, etc. are not equitable.
  The second aspect of this is that people with ASD have specific needs. Generic health, education (mainstream and special), employment, accommodation and disability services do not meet the specific needs of people with autism and ASD. People with ASD need governments to recognise that they need to manage services for people with ASD; and that staff trained specifically to manage, treat and support people with ASD need to provide those services.

- Early intervention
  Discussion identified that existing early intervention services for young children in all states are seriously inadequate. They need intensity and a basis in evidence. They need to treat a child's autism.
  The forum said children with ASD have individual needs. Just as children with cancer require a variety of treatments, children with ASD have a complex needs arising from a disorder that is notoriously difficult to treat.

- Targeted rebates/coverage order/Medicare/health insurance

- Develop and articulate clear pathways

- Service brokerage
  These items aim to show how the federal government can improve access to relevant professional expertise and other relevant services.
  The first item rests clearly with the federal government.
  The federal government can influence the other points through its funding of health and disability services; and through processes like the CSTDA.

- Project recurrent funding for national 'clearing house'/secretariat – info. exchange
  This item has been in the hands of FaCS for several years to my knowledge. As there has been no progress, it has now been raised in the health sector.

- Funding for IT/laptops for each child ($44 million)
  This item applies primarily to students that are school age or above. The health sector may not respond to this proposal.

- National register of autism
  Some of you may recall that the Health Minister told the previous parliament "*the Government does not plan to establish central registers for autism, Asperger's syndrome, or pervasive developmental disorders*." Answer to Questions on Notice No. 2397 in the Senate.

  The WA representative told the forum that this was easily added to a their formalised diagnosis process.

- Post-school

- Adults — coordinated support across …
  These two items are similar. There are issues around employment and accommodation. In my view, these should be taken to other ministers.
  The forum did not discuss issues relating to dual diagnosis of ASD and mental illness … or the possible misdiagnosis of mental illness instead of ASD.

- Nominate a responsible Minister and Department to take responsibility
  This last minute addition was not discussed much. Personally, I am not sure this is a good idea. I want health issues to be the responsibility of a health minister, education to belong to an education minister and employment to rest with an employment minister.
  I would like to see how this proposal would work.

The above is a mixture of history, information and my personal views. I hope it help you to understand what I am doing and why. And you feel I've got it wrong or could do this job better, I hope you will tell me.

A4 Contacts

Update team (newsletter)
edit@a4.org.au

Treasurer (donations)
treasurer@a4.org.au

A4 Convenor, Bob Buckley
convenor@a4.org.au