A4 UPDATE
Autism Aspergers Advocacy Australia

July 2006
Issue 4

Federal Health autism package in the next 12 months

Hansard records that Mr Christopher Pyne MP, Secretary for Health and Ageing, said (15 June 2006):

> … my goal in next year's budget is to work on a substantial autism package to address what I think is a glaring difficulty in the community in terms of parents of children with autism and the children themselves falling through cracks and not getting the early intervention that is needed, not getting the correct early diagnosis, and therefore not being saved from a difficult life when they could have a very productive life. One of my goals in the next 12 months is to work on an autism package.

The challenge for the ASD community is to explain the gaps in services and support to politicians and bureaucrats, how the gaps can be filled effectively and what early intervention is needed. We have to explain how a package can meet the different needs of all the different people with ASD. We have to recognize and explain the varied options that people need, and show how they can all be provided in a politically acceptable manner.

The timescale for federal budgets means we have only got a couple of months to do it. The shape of a "substantial autism package" in Health must be known by October 2006, or it will slide at least a year.

While the federal government is willing to build police stations in remote indigenous communities, it will not build facilities for autism/ASD services. So we need to fit the substantial autism package into existing facilities and services.

We need to stay focused on health issues. What services can a GP deliver for someone with ASD in a 10 minute consultation? Will an Extended Care Plan (ECP) designed by a GP actually help a person with ASD?

We need to make sure government understands how badly existing services fail people with ASD. For example, Centrelink data[1] shows in January 2005 there were 4,333 people with ASD on the Disability Support Pension (DSP). In January 2006, it had risen to over 5,318. That is an increase of 985 (23%) in 12 months. Over 82% of those with ASD on the Disability Support Pension are under 25 years of age.

This data shows most people with ASD are granted a Disability Support Pension soon after they turn 16 years of age.

The education and therapy services they receive fail to prepare people with ASD to participate economically in the community. And the available employment supports do not meet their needs.

It is likely education services fail because children with ASD are not adequately prepared for their education. Nor are they adequately supported through their education. Governments expect teachers to meet both clinical and educational needs of children with ASD. Teachers

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[1] In answer to a Question on Notice, Tues 14 February 2006, in the Senate Finance and Public Administration Legislation Committee Estimates hearing (see http://parlinfoweb.aph.gov.au/piweb/Repository/Commttee/Estimate/Linked/4487-5.PDF pp173-5).

are not trained for this role. No one should be surprised that they are cannot, despite the enormous efforts many of them make, deliver equitable post-school outcomes for their students with ASD. This is a failure of government, not of teachers.

In relation to Health matters, governments and service providers need to understand that a couple of hours per week of "therapy", a few hours of "parent training" and a bunch of generic "supported inclusion" does not address the clinical aspects of the "severe and pervasive disorder" that is autism when it is a severe or profound disorder. That type of service does not lead to equitable outcomes in people with severe language, social and behavioural disorders.

A recent report in Victoria found 1/3 of students with "problem behaviours" have Asperger's disorder/syndrome. There are thousands more students in Victorian schools with "problem behaviours" who are at risk of joining this group of students whose clinical needs were not and are not adequately treated. The report does not discuss the number of students with other forms of autism who have "problem behaviours" and who also do not get the clinical services they need.

Community Services in other states face a growing challenge from families who can no longer cope with their child's untreated autism. Growing (but unreported) numbers of children are forced into state care because the lack of treatment for their autism makes their continued inclusion in a family impossible.

Queensland researchers repeatedly report that adults with developmental delay in Australia have particularly poor health outcomes. They told the AIHW that people with developmental delay (including people with autism):

- have significantly higher than normal mortality (significantly reduced life expectancy).
- average 5.2 serious health disorders and with 2 or more unrecognized or poorly treated.
- experience significant sensory impairment, psychiatric disorders, abuse and chronic pain (dental, musculo-skeletal and gut), over medication, epilepsy (with inadequate review), infections and osteoporosis. The list goes on …
- are at risk of serious abuse.

This information is not really reflected in AIHW publications or known to government. So far, the best we have is that autism and related disorders have the highest reported rate of severe or profound disability.

In relation to autism, health services are governed by the Inverse Care Law:

> Those who need medical care the most are least likely to receive it.

Christopher Pyne MP said to me that it can't all be bad. He chastises me for being so negative despite my saying I think that our ASD diagnosis rates are as good as anywhere in the world.

I am on the record as saying I think most teachers who are responsible for teaching students with ASD are doing the very best they can given their circumstances. Also, there is a tiny band of professionals working hard to help people with ASD.

But funding for ASD services is not keeping pace with rapid growth in numbers so service per client diminishes, which causes everyone enormous stress. And the overall outcome, as is shown by the outcomes observed in terms of economic participation, is especially poor.

The biggest heroes are the families and carers who do their very best to compensate for the massive treatment, service and support deficiencies. Governments depend on their resilience. But inequitable/unjust policies, community prejudices and the chronic lack of appropriate services stretch many of these heroes to and beyond their breaking point.

Until there are health (and other) services that specifically target the aspects of ASD that are severe and pervasive *disorder*, a defining characteristic of DSM-IV diagnosis, Mr Pyne would be unable to identify any government funded health service that is good in terms of effectively treating ASD and achieving measurable outcomes. Hopefully his "significant autism package" will be significant enough, specifically target autism and arrive soon enough that we don't ever find out how bad things really are.

Following is the full section from Hansard (Proof Issue, not yet final). Enjoy!

Mr RANDALL—I would like to address some comments and a question to the parliamentary secretary representing the Minister for Health and Ageing. They relate to autism. Before those opposite consider this filibustering, if they do then they reflect on all parents with autistic children and on a community that is suffering from this huge issue of increased autism—

Ms Gillard—We agree with that, thanks. And we work with the Autism Council, so don't slur us.

Mr RANDALL—In fact, I praise the member for Holt again for his support for autism in the Committee the other day. In terms of my interest in autism, I support a local group called the Unique Mothers, for mothers of children with autism in the Canning electorate. One of the problems is that people with autism suffer greatly because, as I understand it—and the parliamentary secretary can confirm this or otherwise—one of the reasons that autism receives less funding than other areas of health is the fact that it is not considered a syndrome. Because it is not considered as a specific syndrome, it does not receive funding as such.

I know that this is an area that comes under the responsibility of the parliamentary secretary. I receive many representations from parents of children with autism. For example, in Canberra there is a group called A4 which is very active in contacting us in relation to further funding and resourcing for parents of children with autism. My question to the parliamentary secretary is: what programs and funding does the federal government continue to assign to autism? One of the areas that parents of children with autism are continually seeking support on is for early identification and early programs. The earlier you take on the role of identifying and then working with children with autism, the better the results are.
One of the other areas of great need for parents of children with autism is respite. It is not just about respite; it is about flexible respite. By way of an aside, in an adopt-a-politician program in Western Australia, which is largely unique to Western Australia, I have adopted a boy with autism. I went through a formal adoption process in the state parliament to do so, along with other members on both sides of parliament, state and federal, to help people with disabilities. I would recommend to the parliamentary secretary that this program be funded so that it can become an Australia-wide program because it not only helps awareness but also it helps the parents involved in many different ways which I will not go into now because of time constraints.

Flexible respite is needed for when a parent is absolutely at their wit's end. We know that in the past some parents have actually harmed their autistic child because they cannot take it any longer. Flexible respite is something they crave. There is no point in saying, for example, 'You have a respite time next Sunday between the hours of two and six,' because you might not need it then. You need respite when the child is absolutely out of control or the parent has had enough. This stops harm. In fact, I understand there have been cases where parents have caused the death of their child. That is how serious the matter is. I ask the parliamentary secretary, on behalf of the parents of children with autism: what programs and funding have we allocated in this budget and what can we do into the future in terms of this very needy program?

The DEPUTY SPEAKER (Hon. BK Bishop)—Before I call the parliamentary secretary I would point out that it is up to him as to whether he responds after every question or whether he wishes to answer at the end of the session. Probably after each intervention is wise on this occasion.

Mr PYNE (Sturt—Parliamentary Secretary to the Minister for Health and Ageing) (11.13 am)—I am happy to respond to the member for Canning's query. It is well known in this place that the member for Canning has a particular interest in autism and he has lobbied me on a number of occasions about autism. He will be very interested to know that the meeting I had immediately before coming to the Main Committee was with Bob Buckley from A4 and ASA, the national autism organisation. Bob Buckley is an extremely passionate advocate for parents, particularly, and children with autism spectrum disorder. I wish we could do all the things that Bob wants us to do but, of course, there are issues to do with state responsibilities and Commonwealth responsibilities and levels of revenue available to spend on every problem that could be fixed.

Having said that, now that the mental health package is being bedded down and we have had a substantial injection of funds into mental health, I was happy to tell Bob this morning, and I am happy to tell the member for Canning now, that my goal in next year's budget is to work on a substantial autism package to address what I think is a glaring difficulty in the community in terms of parents of children with autism and the children themselves falling through cracks and not getting the early intervention that is needed, not getting the correct early diagnosis, and therefore not being saved from a difficult life when they could have a very productive life. One of my goals in the next 12 months is to work on an autism package.

In this budget, though, I am pleased to tell the member for Canning that the mental health package item to do with accessing psychologists through the Medicare Benefits Schedule means that, after referral from a GP or psychiatrist, psychologists will be able to be accessed by children with autism spectrum disorder. This is an improvement for them and means that they will be able to see psychologists on the MBS when they have been referred by a GP or by a psychiatrist. That is a substantial step forward, and Mr Buckley was very pleased to hear that.

In last year's budget, the member for Canning may remember, we altered the requirements for access to the carers allowance and the carers payment. Many children with autism spectrum disorder were falling through the various definitions in the criteria and we enabled the carer of any child with autism spectrum disorder to have access to carers allowance and carers payment, so that was an improvement for them last year. We are making gradual steps forward in each budget, but I would like to be able to do more for them in next year's budget. One of the difficulties with autism is that it falls between many stools. There is no one department in the Commonwealth government which is responsible for autism spectrum disorder. So FaCSIA has significant responsibilities, DEWR has responsibilities and the Department of Health and Ageing has responsibilities. One of the things we are trying to do is narrow that down so that one area has more responsibility and control. The member for Canning would remember that we had a conference here last year which I initiated with the member for Casey, who is also a passionate advocate for services and support for families with children who have autism. That conference came up with a number of recommendations, one of which was a research project to drill down into what sorts of services would be useful for people with autism spectrum disorder. That has been funded and is nearing completion, and we will soon have the response from the research that arose from that conference we held last year.

So we are making steps forward. We could do a great deal more in terms of respite. One of the problems with respite, of course, is that the services are largely provided by the states under the Commonwealth-State Housing Agreement. Unfortunately, because of that, the Commonwealth has little control over how that money is spent. We would like to have a lot more control. I think there is a chink of light for us in that area, because the mental health package also contains support for 650 new respite places for people with mentally ill children. Therefore, I guess we have broken the dam wall a bit through this mental health package, and we might look to see how we could do that further in areas that affect families with children affected by autism.

Convenor's message

Dear member

Big news in this edition is that I met with Christopher Pyne MP, Secretary for Health and Ageing in mid June. He left the meeting and immediately told his fellow politicians of his decision.

You can read a report of our meeting in a Hansard (see above). Then please send short emails thanking Christopher Pyne MP and Don Randall MP (see To Do List for July below).

We owe a big thanks to our friends at Janssen-Cilag Pty Ltd for organising this meeting with Christopher Pyne MP. They asked me how they could help A4. I suggested it would be a big help if they could get a meeting for A4 with the Secretary for Health. They made it happen and I am very grateful.

An article (page 7, below) invites you to tell you story. Your story is important. Please sit down as soon as you can and write. Your writing is fine … just tell the story. We want hundreds of stories, so get everyone you know to send theirs.

This effort is directed at the Secretary for Health and Ageing. Please let us know of anything you feel needs to be said that relates to ASD to those in federal government who are responsible for health and ageing.

A4's role is to represent all its members and their views about ASD. So outside A4 my role is to represent all the opinions of its members, not just a majority or some particular or selected views. I take this responsibility of the A4 Convenor very seriously. But I can only represent the views you, the A4 members, tell me about.

The Western Australian Autism Register has published some new data. Their 2003 and 2004 report is available for downloading from http://www.autismwa.org.au/autism_register.html .

I appreciate that few people share my interest in such things. Perhaps the most important thing is that the diagnosis rate has slowed and increases since 2001 are small.

While I have no explanation for this levelling off of the diagnosis rate, it is not a surprise. There have been reports from overseas that diagnosis rates are levelling off. Once again, we see the pattern in Australia is like the rest of the world.

Inside this Issue

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The WA register shows fewer than 50% of people diagnosed with ASD also have an intellectual disability.

The Government's respite initiative in the Budget targets people with an Intellectual Disability. People who do not have an intellectual disability will most likely miss out. As mentioned in the last Update, the government is directing services away from more than half of the most disabled group in the Australian community, people with ASD and who need respite but who do not have an intellectual disability.

People with ASD are a major disability group. Many of these people have "problem" or "challenging behaviours". Many need respite services but they will miss out because they do not have an intellectual disability.

The Government developed its Budget initiative and its disability policy without consulting any representative of people with ASD at the national level. And its policy denies many people with severe disability access to services.

If you are a lawyer, or know a lawyer who is interested in helping us raise this issue with the Human Rights and Equal Opportunity Commission (HREOC) please contact me at convenor@a4.org.au.

I apologise that I am unable to report on what your state told me about their services in this Update. Hopefully, I can do that in the next newsletter.

All the best

Bob Buckley

2/7/2006

To Do List for July

I know it is a big ask, but please make an effort this month. Maybe have a working morning tea and get you friends or your support group to do it as well.

1. Email Christopher Pyne MP (C.Pyne.MP@aph.gov.au) saying thank you for your interest in helping people with autism; I eagerly await more information on the major initiative. Please appreciate that ASD is a distinct disorder that needs ASD-specific treatment and services, generic services do not meet the specific needs of people with ASD. Consultation with the ASD community is essential.
2. Email Don Randall MP (Don.Randall.MP@aph.gov.au) thanking him for his interest in autism and for raising it with Christopher Pyne MP with such a positive result.
3. Send ***My Story*** (see below) to A4 (convenor@a4.org.au) by the end of July.
4. Email the CSTDA Inquiry (see page 8 below).

Tell your story to the Minister

In my meeting with Christopher Pyne MP (15 June) it was clear to me that he and his staff do not understand how the life of a person with an autism spectrum disorder unfolds. He asked that we give him a document that describes how people with ASD progress through life.

We have to help them understand. We have to give the information to them personally as they do not have time to go looking for it. We must ensure they have no excuse for not knowing what happens in our lives.

So A4 needs your stories to give to Christopher Pyne MP. Please email me your individual story and I will put all our stories in a big report and give them to the Secretary for Health and all the other federal politicians. If you sent stories before, perhaps you can update and send them again (sorry to keep asking).

Here is what I would like you to send to me.

- First name (optional), suburb and state.
- Month of birth and gender.
- Include a digital photo: at least 640x480 resolution
- Age in years and months at diagnosis with an ASD, and profession of the person(s) who did the first (accurate) diagnosis.
- Any other serious conditions disorders.
- Describe your experience with post-diagnostic services: did you get good information at the outset or did you find out things you needed later, did you get early intervention: and was it adequate and effective (knowing what you now know).
- Briefly describe your experiences with schools (both primary and high school). Include the good and the bad. But if you mostly describe good stuff, the government will think there is nothing to improve.
- Describe community services: respite, community access, supported inclusion, behavioural support, etc. Especially mention services you needed but could not access such as case management, individual advocacy, legal aide/support, …
- How does your ASD affect the rest of your family and how they live?
- People with experience of tertiary education, employment and post-school options should describe those.
- Finish with your personal goals and the barriers that are preventing you from reaching your goals.

Have the person with ASD tell the story, as much as possible. If you can sum up each of the above topics in one or two paragraphs it would be really good. Ideally each story will be between one and two A4 pages. If you want to send a separate carer's story, please do so.

Please do this immediately. Do not put it off. Try to get your story to me by the end of July.

Your story will be edited into a major report. That means we will fix any spelling or grammar errors. We may edit it down to 3 A4-pages if you send us more than that. The final report will be a public document.

A4 renewal: call to join an A4 committee

A4 needs a bunch of new committee members. Please help us?

Are you interested in helping people with ASD? Will you share your views on any of the following topics with a small group? If so please contact us? Or do you know someone who should be involved? If so, please get them to nominate.

A4 is forming subcommittees to focus on the following suggested areas:

- ASD (and A4) publications/promotions (join in and help produce the Updates and maintain our website … we need you now),
- Education (DET issues and liaison)
- employment (DEWR liaison) and adults with ASD,
- health matters perhaps with early intervention as a separate group,
- disability, welfare and carer services (FaCSIA liaison)

We need people who will discuss these issues. You do not need existing knowledge. Are you interested in asking questions, discussing answers and strategies? With a few more people like you we can achieve so much more.

So if you are interested in one or more of these subjects, please drop us a line. This is a chance to make a difference for people with ASD. And to work with some great people.

We will get the groups in touch via email. Then we will let the groups get on with it. Or we can help them get going.

Inquiry into the funding and operation of the Commonwealth State/Territory Disability Agreement

It would be fantastic if the Inquiry received thousands of email submissions about ASDs. If you don't have time to write an individual submission you can register your concern in less than a minute by using this *pro forma*. Feel free to circulate it to your friends and ask them to register their concerns too. It is important that the Inquiry understands that the community wants a fair go for Australians with ASDs.

Simply cut and paste the *pro forma* below onto an email, type your name and contact details at the end of the letter, then send it to this address community.affairs.sen@aph.gov.au (which also appears at the top of the letter).

If you have any questions, please email Wendy Kiefel (A4 steering committee member) at kcosmic@optusnet.com.au

Thanks for your help, the more submissions, the louder our voice!

community.affairs.sen@aph.gov.au

Re: Inquiry into the funding and operation of the Commonwealth State/Territory Disability Agreement

Dear Committee Members,

I write to you as an Australian concerned about Human Rights for people with Autism Spectrum Disorders (ASDs).

The Australian Institute of Health and Welfare cite ASD as the disability most likely to result in severe impairment.

Sadly, outcomes are poor for Australians with ASDs in terms of education, employment, independent living and quality of life. This correlates with Australia’s paucity of health and disability services addressing ASDs.

For example the Victorian DHS report *Responding to people with multiple and complex needs* in July 2003 identifies the;

"lack of targeted responses to individuals with autism spectrum disorders, particularly Asperger’s Syndrome. These people are often identified as falling into service gaps, frequently deemed ineligible for both mental health and intellectual disability services."

It is profoundly unjust that the Commonwealth States and Territories Disability Agreements do not to make adequate provision for Australians with ASDs.

If Australia is fair dinkum about a fair go for people with disability, the CSTDA will

a) formally recognise Autism Spectrum Disorders as a distinct category of disability

b) compel the States and Territories to provide effective disability services for Australians of all ages with ASDs.

I formally request that the Members of the Senate Community Affairs References Committee take steps to ensure this happens.

Yours sincerely,

A Parents Advice – Part Two

So, with our son finally out of the school environment which all but threatened his life, we sought refuge in another high school which looked very promising.

Initially our son was only able to attend a couple of days a week simply because he didn't trust the school environment and, more to the point, he didn't trust teachers.

We were very lucky to find three teachers who with love, care, and attention to duty, brought our son "back".

Sir Isaac Newton's third law states that: To every action there is always opposed an equal reaction.

Following that line of thought we thought it best to write to the education department again, to wit:

We are writing to express our delight at the treatment our son is receiving at his new high school.

You will remember we wrote to you late last year regarding our disappointment at the way in which (his previous school) handled the management of our son during the 2000 school year.

Our son was diagnosed with Asperger's Syndrome in October 1999.

Both the teachers and the support staff at his new school have shown him and us every consideration. The level of support and understanding provided to our son has changed him from an angry, frustrated and at times violent child who was seriously under-performing, to a happier child who, with the appropriate level of help, it would seem is performing scholastically at least very well.

It didn't happen overnight. Getting him to trust teachers again was difficult, but has been achieved. There have of course been some behavioural problems, which again the school has handled with patience and understanding, tempered with the appropriate levels of discipline.

The staff have been willing, and in fact eager, to learn as much as possible about Asperger's Syndrome which has helped not just our son, but also themselves.

In the short time our son has been at the school it has:

Implemented and maintained many if not all of the suggested strategies for Asperger's Syndrome, and successfully introduced strategies of its own.

Stepped in to protect our son from any sign of bullying or harassment to which Asperger's Syndrome children are particularly vulnerable.

Gone out of its way to make staff aware of Asperger's Syndrome and of strategies to help our son.

Been in close and regular contact with his tutor, a qualified special education teacher, and is working with him to further help our son.

To say that after last year this level of service and support has possibly been a lifesaver is an understatement.

In particular, can we bring to your attention our appreciation for the support from our son's home group teacher, the Year 8 coordinator and the special-needs teacher. Their patience and willingness to accommodate our son during what has been a difficult time for all of us has been outstanding. All three have responded to our frustrations, and in particular our son's frustrations, with a professional and personal zeal that has gone far beyond our hopes and expectations.

Both teachers in particular have gone out of their way to keep us informed of our son's progress and their strategies, to the point on one occasion of telephoning us after-hours just to let us know he had had a good day.

Their generous efforts have gone a long way to restoring our son's mental and physical health.

Above all, they have helped our son restore some dignity.

We also thank you for your support and interest in this matter.

Yours sincerely...

It is worth delivering praise when praise is due, and on this particular occasion both his teachers were singled out for praise in the appropriate quarters. His special needs teacher was also singled out for special praise which included, sadly for us, being promoted to an administrative position at head office. I am informed she is making great ground in improving the situation in schools for children with a handicap – and in particular Asperger's Syndrome - and openly acknowledges her experience with our son as the primary trigger.

His home group teacher has also acknowledged that her experience with our son made her a better teacher.

These individuals need to be encouraged, and even cloned. There are simply not enough of them.

So with our son firmly, and happily, ensconced in his new school the slightly less bumpy road began to be travelled.

But to quote – this time Robbie Burns – "The best laid plans O' mice and men gang aft aglay", or in other words, Murphy Strikes!.

Autism in Mainstream

Hi everybody,

I just received a letter back from the Minister for Education refusing to meet with me since I have already met with John Minns and Craig Cleaver, who are currently investigating the proposal for a mainstream Special Education class for high school high-functioning autistic and Asperger's students. Although I have minutes of that meeting, the bulk of it was my detailing from pre-prepared notes. I am detailing here anything relevant that they added to the discussion. My detailed notes run to eight pages but my pre-prepared notes (most of you, if not all, should have a copy, I will re-send on request) have everything relevant.

I have not heard from either John Minns or Craig Cleaver since our meeting on 24 April.

The gist of the meeting was primarily myself and my husband outlining the proposal and explaining why no other option within mainstream has been working or is likely to work as well. We also described other concerns with DET's failure to appropriately assess or meet the needs of children like ours. We used examples from the education of both our sons - one is 12 and now in Year 7 through Distance Education, the other was pulled out of Year 12 mainstream due to long-term failure of DET to appropriately support him. There was no accountability in DET so they had no record of their failure in this and maybe countless other cases. Our older son completed his HSC through Distance Education. He is now 22 and has experienced a much higher standard of support at TAFE.

The proposal - the class would have a maximum of 9 students, be held in a mainstream high school with a classroom to spare (there are a few in Sutherland Shire). There would be a Special Ed teacher and a teacher's aide (not necessarily trained in autism, either of them, but trained in Special Education). The students would attend mainstream classes within their interest areas/capability but would otherwise complete curriculum material in the Special

Education/Home Room. This Home Room would also be a bolthole for the students on days/times when their coping skills are less. Mainstream teaching staff on site to provide educational subject support. During break times the students would mingle in the playground with mainstream students (I'm not happy about that one, I do believe there needs to be playground supervision to prevent discrimination/bullying), educational and social programs to be tailored to each student's needs.

The Department's response at the meeting (and we genuinely appreciated the honesty of this response) - it will cost the equivalent of three teachers' aides to staff the class as proposed (which is the minimum requirement legally). We would need to be cost-neutral, ie the students entering the class would need in total to be already costing DET the equivalent of three full-time teachers aides. Nine students each with an average of one third of a teacher's aide full time for a week (ie two hours a day, five days a week) would just cover it.

Problem - a number of students expressing interest are already 'outside' the system in home schooling or Distance Education. There is no associated DET cost that could be factored in; to set the class up so these kids could benefit is NOT cost-neutral for the Department. We need to recruit kids currently in the system and costing the Department money, IN THIS DISTRICT.

Problem with this - we have no contact via educational channels. Confidentiality rules mean we cannot access DET records and we're fairly sure DET are not going to approach parents with feedback to this proposal. They could do without the bother of activist parents wanting change and new classes at a time when such classes seem to be a retrograde step in policy. We would be taking kids out of full integration and putting them IN to a Special Education class, and from a DET point of view this is backwards. From a parental viewpoint, this would only be done if full-time mainstream were not working for the child as successfully as this proposed class would.

So, how to contact other parents and let them know of this proposal?

We have contacted local autism support networks, but this only reaches those parents who attend such groups and are on their email list. We have contacted ASPECT's website forum (and have just done so again). From these forays we have gleaned only about eight interested parties covering a wide age range and geographic distribution. We still don't have enough in the group we need. The wide range in age will be helpful in the future to demonstrate an ongoing utilisation but for now, we would only have about four ready to go into an autism class. Not enough. We need more. We know they're out there, so the next step is going to be contacting the media. Anybody with connections, please step forward. Meanwhile we've also been asked to organise a meeting for those already expressing interest, including the health professionals who are also supporting us.

If you are determined to commit to this cause and want your child's name down for the likelihood of such a class, will you please send an email affirming this to John Minns at:

john.minns@det.nsw.edu.au

In order to ensure that your involvement is independently recorded, please Bcc the email to this address where I will note the date and identification on my files.

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Provision of Services for Autistic Children in Australia

andrew@pecante.com

3 April 2006

The Hon. Peter Costello, *MHR*
Treasurer

The Hon. Tony Abbott, *MHR*
Leader of the House
Minister for Health and Ageing

The Hon. Julie Bishop, *MHR*
Minister for Education, Science and Training
Minister Assisting the Prime Minister for Women's Issues

The Hon. Mal Brough, *MHR*
Minister for Families, Community Services and Indigenous Affairs

The Hon. Joe Hockey, *MHR*
Minister for Human Services

The Hon. John Cobb, *MHR*
Minister for Community Services

The Hon. Chris Pearce, *MHR*
Parliamentary Secretary to the Treasurer

The Hon. Chris Pyne, *MHR*
Parliamentary Secretary to the Minister for Health and Ageing

The Hon Pat Farmer, *MHR*
Parliamentary Secretary to the Minister for Education, Science and Training

Parliament House
Canberra ACT 2600

Dear Ministers and Parliamentary Secretaries

Provision of Services for Autistic Children in Australia

Recently (late Dec 2005), we received the unfortunate news that our now three year old son, Joshua, has autism. It is an understatement to say that it has been a very difficult time for our family. Despite having to come to terms with his lifelong diagnosis, the many challenges ahead that face both him and us and the uncertainty surrounding possible treatments, we remain positive about his future.

However, my son's ability to function in this world can only be realised by a commitment from himself, his - parents, family, friends and carers. It is likewise essential that the Federal Government commit to this task of supporting young Australians with this lifelong disability.

At this early stage it has become clear from agencies, providers and parents of other autistic children that the level of funding provided by State/Territory and Federal Government(s) does not match what is required for our child. It seems another case of our leaders from both sides of the political fence, State/Territory and Federal, shifting the blame for these inadequacies to each other. Meanwhile, every working day ten more Australian families (53,000 people Australia-wide are affected) learn that they have a child with autism and that their lives will never be the same again. We need a long-term and sustained commitment that reiterates the value of these children.

Now is the perfect moment, with a record budget surplus, when the Federal Government can declare that children with autism matter. **These are the forgotten children of Australia**. This is not just about platitudes or parliamentary motions, but a true partnership, both legislative and financial that can occur between the Federal, State and Territory Governments.

Recently we have heard commitments from the Council of Australian Governments (COAG) about tackling mental health issues. I have heard arguments about the value of early intervention, the growing cost to society and how these people matter. All of this and more can be applied to children with autism.

Rather than just argue, we need to implement some meaningful recommendations such as

- Rapid review of existing inter-government/inter-agency disability service level agreements with respect to Autism Spectrum Disorders (ASD) services and programs. This could encompass an Australia-wide audit of autism-related services.
- Creation of a new peak National Autism body rather than a federated council (modelled on the UK) that would provide greater coordination and work to minimise inequities in services across the country. *The Hon. Tim Fischer would make a great inaugural convenor.*

We are all aware that allied health workers such as psychologists, speech pathologists and occupational therapists provide critical treatment for autism. While it is true that some Medicare allied health service rebates are available for conditions treated by GPs through an Enhanced Primary Care (EPC) plan, few (if any) sufferers are offered EPC plans and the rebates because GP's do not treat autism.

Autism sufferers and their families compensate for the lack of public services (my son is lucky to get a few hours a fortnight of State funded treatment) by using private services typically costing $100 to $200 per hour. Paediatricians say that speech pathology, psychology, occupational therapy and behavioural therapies are medically necessary for children to minimise their lifelong disability – **yet these services are mostly unfunded by Medicare.**

The Australian Tax Commissioner issued a special ruling that allows some treatment for autism to be claimed back through the tax system. Wealthy families with good accountants are the beneficiaries. This isn't a fair or equitable arrangement.

Chronic under-resourcing of autism-related public health services has been allowed to perpetuate. This causes considerable financial hardship for the parent/carers of children with autism. Adding to this financial pain is the fact that there is considerable confusion in the community about allied health services and Medicare. Misleading messages do not help "for the first time there is now a safety net to support all Australians against high medical costs for medical services provided outside hospitals" – this is not the case for autism sufferers.

Consequently, we further recommend:

- Make the funding of autism programs and interrelated support a full Federal responsibility under Medicare with full coverage of scheduled fees. *Health Professionals could only charge scheduled fees and are strongly encouraged to bulk-bill for people officially diagnosed with ASD.*
- Offer each family with a child/adult officially diagnosed with ASD a meaningful level of Medicare funding for accredited State/Territory early intervention/transition to School programs (including speech pathology and occupational therapy) from 1 July 2006. Offer the provision of retrospective entitlement in specified instances.

With these measures in place the delivery of autism-related services by the Commonwealth and States/Territories could be first class (and consistent across the country). The real winner will be children like my son.

Opponents of this proposal will argue about the need for services for other children with special needs, we should at the outset all agree that their funding levels and support need to also be re-assessed, but we must start valuing our children and autism is as good a place to start as any. Particularly, as its incidence is now so prevalent.

My son and the quality of his life depend on your foresight and the generosity of the Australian taxpayer. Please don't make your response (if you indeed bother to respond) a long litany of what you believe that you and/or others now offer, or the blame game ("it is a State responsibility"). We would ask that you please respond to the proposed items above directly and hopefully offer us and our family real solutions and not just sympathy. It would be your legacy if you could deliver something of substance for/to children like our son. **The 2006/07 budget is not too soon to set a new approach in place.**

If as parents we can in the years to come, look at our son and honestly say that we did everything possible to make his life more meaningful and that this commitment was matched by a compassionate Federal Government (in partnership with the States/Territories) – then we will all be the better for having listened and responded.

Thank you for listening to these concerns and seriously considering our proposals.

We look forward to a prompt but considered response from each of you **and** the government as a whole.

Yours Faithfully

Andrew and Janet McLean

P.S. I acknowledge the use of statistical material on the A4 (Autism Aspergers Advocacy Australia) website.

A4 Contacts

A4 is a grassroots organisation. All A4 activity, such as publishing the Updates (newsletters), is done by volunteers. Please understand that A4 volunteers may have no training or qualifications for their various roles. They do the best they can for people with ASD, their families and associates. A4 welcomes assistance and constructive criticism.

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