UPDATE

A4 Autism Aspergers Advocacy Australia

October 2005
Issue 8

Inside This Issue

Enhanced Primary Care Plan

Mr Abbott MP, federal Minister for Health, sent a letter to all GPs (see http://www.a4.org.au/documents/TA2GPs.png). Some of the detail is available from the Health Department website at http://www.health.gov.au/internet/wcms/publishing.nsf/Content/pcd-programs-epc-chronicdisease.

The government intends that children who need clinical help to participate in their community, either now or in the future, should be able to get clinical help through the health system. If you have a child with ASD who needs help in any of the allied health areas, including speech pathology, psychology, occupational therapy, etc., then this scheme may be worth trying.

An article on the GPs website (see http://www.racgp.org.au/afp/downloads/pdf/august2004/20040803davis.pdf) says GPs have a role in helping a child who has

> *‘behaviours of such intensity, frequency or duration that the physical safety of the person or others is placed in serious jeopardy, or behaviour which is likely to seriously limit or deny access to the use of ordinary community facilities’*

Children who run or dart away near a road, or children with little road sense and also abscond at every opportunity, place their physical safety in serious jeopardy. A child whose behaviour “is likely to seriously limit or deny access to the use of ordinary community facilities”, that is community facilities such as child-care, preschool, school or after-school care, clearly fits such a description. Similarly, this description fits a child who does not attend to the teacher in school and lacks “access to the use” of school and education services. A child whose behaviour limits access to a public swimming pool, cinemas or participation in junior sports could also fit this category. Preferably, for people whose autism alone or combined with their anxieties results in severe dysfunction, it is best to act well before “the physical safety of the person or others is placed in serious jeopardy”.

Start with taking your child to your GP and ask for help. When you make your appointment say that you specifically want to talk about an EPC for your child. Prepare for your visit. Write a list of your most serious concerns and put the list in priority order. Plan to ask your GP to develop an EPC for your child that provides the individual intervention for your child's highest priority needs.

Some children with autism find a trip to the doctor is very difficult[1]. It is crucial that your GP understands the difficulty you and your child experience. So if you need to, prepare for the visit to the GP … and be prepared to persist with the visit. Even if you don't get much done during your first visit, hopefully the experience will convince the GP that you really need good professional help.

If cost concerns you (I expect it will for most people), discuss the cost with your GP. Ask that cost is included in the planning process. At first you may not know the cost of particular services but you can call and get costs for any service before you visit a service. Your GP may not know the cost of services so you may have to get the cost information yourself. You can send the cost to your GP to be added to your EPC.

Keep in mind that an effective EPC will be an ongoing process. Your GP may not know much about ASD and its treatment. If your GP is unwilling or unable to help, or to acquire sufficient knowledge, then you may need to find a more suitable GP.

Convenor's message

Dear A4 member

It is now 3 months since Mr Christopher Pyne MP held the National Autism Forum. At the forum we were told that the Facilitator would take about 2 weeks to prepare her report and that it would then be circulated. Department staff and the advisor in Mr Pyne's office told me recently that the report will be available soon.

Before the forum, I received several emails from the Health Department. The first said parents of children could access allied health services (that is psychology, speech pathology, OT, etc.) through the government's Better Outcomes in Mental Health Care initiative. A subsequent email said …

> the Better Outcomes Initiative is designed to support GPs in the management of their patients with mental health conditions. … The program itself does not extend to developmental disabilities …

and

> I understand from our clinical advisors that autism requires a multidisciplinary approach to care and in this respect the EPC care planning items are probably better suited for managing the condition than the Better Outcomes Initiative. This also allows limited access to allied health services.

The Department ignored repeated requests for the precise basis of their decision to not include developmental disabilities in the program. So I requested, under the Freedom of Information Act, a copy of all the advice provided by clinical advisors to the Health department relating to autism, ASD, PDD and developmental disability. Hopefully, we will soon see what advice they received.

The national event for carers, Walk a Mile in My Shoes (see http://www.walkamile.net/), happened around the country. In Canberra, quite a few federal politicians from all sides put in an appearance. Both the Minister and shadow minister for Disabilities heard from an articulate group of carers. Autism featured prominently. The audience responded kindly to my contribution (and you might have glimpsed me briefly on Ray Martin's show that night). To her credit, Kay Paterson, the Minister for Family and Community Services, stayed to hear forthright descriptions from carers who held her responsible for their dire circumstances.

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[1] Doctors and dentists are "community facilities" … so if your child has difficulty accessing them, they need professional help to learn to access these services as a basic life skill.

I am sure our members would appreciate seeing a report from each state. If you attended the Walk a Mile in My Shoes event in your state please would you write a short description and send it to edit@a4.org.au?

Carer issues are attracting some attention. Stories of desperate carers and desperate situations abound. See for example, the recent editorial in The Age http://www.theage.com.au/news/editorial/carers-struggle-without-a-break/2005/09/18/1126981944167.html. Many of the stories relate to people with ASD and their carers. An article (see Member's Outrage below) told us that the Victorian Department of Human Services cannot look after a 15 year-old so he will be put in prison instead. Similar stories abound in NSW and Qld.

Each story provides you with an opportunity to write a comment to the newspaper editor, and to send a copy of the article and your comments to all your political representatives. Maybe you can get your friends and family to help in this way, too.

In the meantime, some families are getting some help through the EPC. The article below provides background and information on how to get these services.

Four Corners on ABC ran a BBC story on Autism and MMR vaccination (see http://www.abc.net.au/4corners/content/2005/s1456198.htm). Four Corners did not contact either A4 or ACA, the two national ASD organisations, about the story. As usual, the journalists did not reach a conclusion. I suggest the clear conclusions are:

- There is insufficient research into the causes of autism and related disorders
- Australia was not mentioned in the story reflecting that no relevant research is conducted here
- Irrespective of the cause, treatment for any chronic dysfunction due to ASD is rarely available

The story provoked a very predictable discussion in the subsequent online forum.

Regards,
Bob Buckley
15 September 2005

Member's Outrage

An outraged A4 member sent me this story from the Herald Sun.

Autistic teen in custody

By CHRIS TINKLER
04sep05

STATE authorities have washed their hands of an autistic boy charged with a string of sexual assaults while in their care.

The boy, 15, who has a mental age of 11, was this week remanded in custody with hardened criminals, despite police saying he could be at grave risk.

It came after the Human Services Department, which has care of the boy, refused to place him in a secure welfare home if he was bailed.

Carers also told a Melbourne Children's Court hearing they could not control him if he remained in his care home.

Yesterday the boy's father said the department's actions were "pathetic". "He'll be eaten alive in there," he said.

The boy, who is small for his age, suffers from autism and other intellectual disabilities.

The court heard he had been charged with four sexual assaults on women aged 15 to 32 on trains and at stations in the eastern suburbs.

On August 25 the boy left his home again and was alleged to have committed two more sexual assaults.

Police told the court they considered the best option was to extend his bail in secure welfare, where he had been sent after his August 25 arrest, until the case was properly heard.

But the Human Services Department refused to hold the boy in secure welfare.

And court was told they could only "encourage" the boy to stay at the care home. The magistrate said custody was the only safe option. While we do not know the full story, we do know that deinstitutionalisation closed institutional settings that previously were designed to accommodate people with challenging behaviours and **Treasuries around the country absconded with the funding**. The institutions were less than ideal but may have been (and by most accounts were) better than prison for these people. While skills were outdated, trained staff, especially nursing staff, were employed to work in these places.

The story on A Current Affair, the night of the Walk a Mile event, showed a child whose family is no longer able to cope with his untreated autism. The TV story showed his place in our modern so-called “inclusive society” is an isolated setting adapted to contain him.

Governments and the community today demand that families accommodate and manage the most extreme behaviours associated with untreated behavioural problems. Most families get minimal support (more often criticism) from the community and many families are just worn out, and some are unsuited and unequipped for the role. The current system for people with severe or profound behavioural issues is designed to push family carers to live at the limit of their endurance, in conditions that may amount to torture (such as extreme sleep deprivation) and slavery (excessive hours or work and grossly inadequate reimbursement) for family carers.

In practice, this so-called “inclusion model” insists on “including” all children, many who are utterly unprepared, in mainstream settings. Instead of recognising that some children need intensive programs that target specific skills for life, the system denigrates and dissuades people from approaches that effectively target crucial skills in an initially segregated setting … even if the goal is to improve a person’s functioning and achieve a maximal but limited level of inclusion in the long-term. Despite clear evidence that some people do not fit in, “inclusion” ideologues insist everyone should be included from the outset. Those who fall by the wayside, and their carers, are utterly abandoned.

Parents used to be told, when their child was diagnosed with autism, just put the child in an institution and get on with your life. Professional staff was trained to devise and supervise programs for those in such care. Nursing staff were trained to care for people with chronic mental retardation, developmental delay, autism, etc.

But purpose-built settings with trained staff are no longer an option for parents. Hopefully, many children with autism who would have been sent to an institution now have a better life as part of a family. We hope most families do as well or better than the old institutions did, for these children. But we do not actually know. We do know adverse effects on some families and family carers are enormous and consequent outcomes are extremely bad. People with autism do not get the treatment they need. And family carers do not get the support they need and deserve.

Economic rationalists think they have saved the cost of all those expensive institutions and special school. But their simplistic cost models conveniently ignore all the benefits, achievements and savings due to special settings. And they ignore the real cost of isolating family carers from the community.

Family carers do their part as best they can. When will governments meet their part of the mutual obligation due people with ASD? When will we see appropriate, timely and effective treatment, education, employment, and support and accommodation services for people with ASD?

A4 members should be outraged. Now family carers face huge demands right around the clock. They have to live with the full and dire consequences of every slip, imperfection or misjudgement in their over-arduous care provision. In many cases, neither carer nor caree has a future they can look forward to. Thus our community has created a chronically deprived underclass.

If you are outraged too, please tell your political representatives how you feel. Send them a short note saying you are outraged, and include a copy of this article.

ACT pollies won't meet autism representatives

The last ACT election was one week after the last federal election. The new Minister had a 30 minute meeting with an ASD representative in January 2005. At the meeting, the representative raised concerns that there was no evidence funds previously allocated for therapy services for children with autism/ASD were delivered as intended. He asked for 6 months to settle into the job.

In May 2005, the ACT Budget continued the previous practice of allocating funds for people with autism/ASD to programs that provide generic services. The autism/ASD community has repeatedly told Ministers of their concerns that such a funding model simply does not reach children with autism/ASD. Successive ACT Ministers for Disability have failed to find any evidence that funds intended to provide therapy for children with autism/ASD have increased crucial treatment or therapy for children's autism/ASD.

When representatives asked to meet with the Minister in July, they were offered a meeting with a ministerial advisor instead. The advisor invited a number of bureaucrats to the meeting. The bureaucrats were late to the meeting and the advisor then left the meeting after 10 minutes.

The representatives asked for another meeting. The ACT Minister for Disability wrote back that he was too busy and would not meet ASD representatives in the foreseeable future.

The representatives wrote to the Chief Minister and Treasurer asking to meet with them. Initially, the Chief Minister's office acknowledged receiving the request, but did not respond. After several emails and no reply, a representative asked the Chief Minister on talk-back radio would he meet. The Chief Minister said he was not aware of the emails addressed directly to him requesting a meeting. A representative called his office several days later. His office said they were getting advice "tomorrow" from "The Department", and they would call back once they got the information. A week and a half later, they had not called back. The second time, the Chief Minister said autism/ASD representatives had plenty of access to their political representatives.

The ACT Chief Minister regards one 30 minute meeting, and an abortive 10 minutes with an advisor, as all the access to political representatives that people with autism/ASD deserve for "the foreseeable future".

The ACT Autism Association wrote to the Minister for Disability asking that ASD be represented on the ACT Disability Advisory Council. He wrote back in April saying there were no vacancies on the Council. In September, the Disability Minister announced the new membership of the ACT's Disability Advisory Council. Again, ASD is not represented despite the previous request and the significant numbers of children being diagnosed with ASD in the ACT.

On talkback radio, the ACT Deputy Leader (and Treasurer) told a caller that membership of the Disability Advisory Council is a matter for the Disability Minister. The Deputy Leader of the ACT government indicated that autism/ASD representatives try to talk to the Minister, who has written that he will not talk to them in the foreseeable future.

He told another caller that the ACT government already provides all the services children with autism/ASD need. He made this remarkable, apparently omniscient, claim in the absence of any assessment or measurement of need or identification by the ACT government of the actual funds spent on services for autism/ASD.

The way senior members of the ALP government in the ACT treats people with autism/ASD and their representatives is deeply disappointing if not undemocratic.

Currently, ASD representatives are negotiating for a meeting with a couple of ALP backbenchers in the ACT. They may also try to meet with the Education Minister, whose office has been more responsive, later in the year. Several representatives are meeting ACT bureaucrats about some specific concerns, though nothing will come of this without the impetus of political leaders.

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Ask for it: development of a health advocacy intervention for adults with intellectual disability and their general practitioners

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SUMMARY

Two per cent of people in Australia have intellectual disability and the adults in this population often have poor health status. This poor health can be partly attributed to communication difficulties encountered by people with intellectual disability and also health professionals in consultation settings. The design and development processes of an educational intervention to improve communication between patients, general practitioners (GPs) and also advocates in a population of adults with intellectual disability are described. The design process was collaborative and involved adults with intellectual disability, GPs, parents, support workers and other professionals. It was a nine-step development process and led to the final communication tool package, the *ask* (advocacy skills kit) 5-year health diary and educational session. As a result of the collaborative design and development processes, this diary included qualities not found in most other medical record keeping systems: visual appeal, advice on how to be a health advocate, utility for a range of users, privacy, portability and sufficient capacity to record personal patient information which enhanced communication between doctor, patient and advocate. It is proving to be very popular. Clear implications were found for applying established criteria and incorporating the needs of users in the design of educational interventions in the intellectually disabled population. Health promotion tools aiming to improve the current poor health status of adults with intellectual disability should be developed further.

Dear Prof. Lennox,

How do I get hold of an ASK (see below) to assess it for its suitability for people with autism/ASD? Would you consider it appropriate for this group?

Regards
Bob Buckley
Convenor - Autism Aspergers Advocacy Australia

Hi Bob,

We are continuing to trial the Ask and will for some time, a consequence it is not available at this time or for the next year or two. It would be useful in ASD however the concept is the key thing.

Keeping records which are accurate and accessible is the key. I would recommend you compile an ongoing record for your son or daughter that draws upon what information you have from various health and other assessments. A very medical version of a tool for data collection is available from the CDDH Monash Uni - at their website. While it does not contain the advocacy component and it has the key medical elements. The one form Monash was developed by Mary Burbidge who herself is a mother of a daughter with a disability and she is also a GP.

Hope this helps

Nick
Associate Professor Nicholas Lennox
Queensland Centre for Intellectual & Developmental Disability,
School of Population Health,
http://www.sph.uq.edu.au/QCIDD

Woodbury School

A meeting was held on Wednesday 12th October at 7.30pm at the Lane Cove West Bowling Club, Burns Bay Road, Lane Cove, Sydney. This was a general information evening about the school which is expected to open in 2006. Woodbury will be an ABA-based school for children from five years old. A core group of parents, including families who initiated ABA being available in Sydney by bringing out a CARD supervisor, have been the driving force behind the establishment of this school, together with Elizabeth Watson of the Lizard Children's Centre.

What is WOODBURY?

Woodbury will be unique in its ability to offer Australian children with autism an exceptional educational approach.

We aim to:

- establish an initial educational facility for 20 children providing trial research base;
- expand educational facilities throughout metropolitan Sydney;
- provide educational outreach services for the rural and remote autistic community;
- provide ABA/behavioural management training facilities for educational professionals and care givers;
- establish www based information site detailing current management methods relating to autism.

http://www.woodburyautism.org

PUBLIC NOTICE OF NEW SCHOOL

FOR CHILDREN WITH AUTISM

Woodbury Autism School will commence operation in 2006.

We are seeking families interested to enroll their child for first term 2006 (or beyond), and people willing to help develop an important new resource for children with a disability.

HELPING SPECIAL CHILDREN SHINE
WOODBURY
AUTISM EDUCATION AND RESEARCH

Woodbury School - for children with autism and related disorders. Offers an education based on ABA teaching method. Enrolment ages 4 years to 14 years 6 months

School to be located at Building 11, Balcombe Heights Estate, Seven Hills Rd, Baulkham Hills.
(5 mins from Windsor Rd Exit on the M2)

If you have a child with autism or a related disorder, or you represent an organisation for children with disabilities including autism and related disorders you should have a look at Woodbury. You will learn everything you need to know to enable you to make a decision about whether Woodbury will be suitable for your child OR your organisation to recommend to parents of children with autism and related disorders.

*If you want to know more about Woodbury visit our website**:** www.woodbury.org.au*
or write requesting more information to:
The Administrator, Woodbury,
GPO Box 488, Sydney, NSW, 2001

WOODBURY AUTISM EDUCATION AND RESEARCH ABN 58009 441 755

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Letters / Emails

Bob

I am interested in why you would include such an insulting and ill-informed 'article' in the A4 newsletter. I am of course referring to Karen Pettengill's comments published by Dan Olmsted.

Statements like this are simply untrue:

'No child with autism ever went undiagnosed'

From my practice as a Developmental Educator I can point out many clinical examples of children going undiagnosed for many years and I'm sure many other professionals, diagnosticians and parents could also give examples of children going undiagnosed.

And this utterly sickening:
What if you announced tonight that 1 in every 150 children were being abducted from their beds every night? Parents would be screaming for the government, the police, somebody to do something. Well that is what is happening, except they are only taking our children's brains and leaving the body behind.

Would you refer to a child with autism like this – a body without a brain?

Articles like this are alienating for all concerned with the autism spectrum.

I refer you to the recent New Scientist article 'The Autism Epidemic That Never Was' for a different view on this issue.

I'm sure you may well be aware of the recent death of a five year old boy during chelation 'therapy'. It is the rise of sensationalist 'journalism', dubious research, and profiteering that has lead parents like the parents of this boy and parents like Karen Pettengill to believe *'that the increase is real and it is most likely due to an environmental assault such as vaccines'* and that the only cure can be found in further assaulting a child.

The saddest issue here is that so many people are being lead into a debate on the premise that a child with autism is inherently bad and that one without is inherently good.

These views will get us nowhere when we are trying to do is construct a support matrix that will serve all people with autism and their families.

Regards
Katharine Annear

Hi Katherine

I'm sorry the article upset you so much. Please understand that I do not edit A4 Updates ... I did not include the article you refer to. I am just the messenger here. My role is to mail out the newsletter. So please don't shoot the messenger.

I agree with you that plenty of children with autism (presumably Autistic Disorder) went undiagnosed in the past. I have plenty of Australian data showing that to be quite clearly the case. For example, the ABS Survey of Disability, Ageing and Carer's 2003 found 3.7 times as many adults with autism/ASD as it found in 1998. Clearly, there were lots who were not diagnosed previously. And there are many more adults yet to be diagnosed. Clearly, there has been chronic under-diagnosis in the past.

But there are 16-20 times as many children diagnosed with autism/ASD as there are adults. That level of past under-diagnosis is not explained ... where are all the adults with ASD? No one has found that level of ASD in an adult population anywhere in the world. So there is no evidence that there has not been an increase. I'll try to get a copy of the NS article you point to but I expect it just trots out the usual misinformation and absence of science that also characterises that side of the argument. Frankly, proponents on both sides of this debate behave despicably.

I am not "aware of the recent death of a five year old boy during chelation 'therapy'". Where was it? Where do I get the Coroner's report on this matter?

I am concerned that in Australia, evidence shows people with developmental delay have worse health outcomes than the Aboriginal population ... which is a national disgrace. I am deeply disappointed that our health system refuses to treat autism, HREOC continues to ignore the concerns of the community over the issue and the so-called legal system denies people with ASD basic human rights. Professionals and bureaucrats misrepresent and ignore strong evidence on effective interventions; and blame parents for every adverse outcome, when parents are doing their very best for their children based on the information available to them.

Many parents of children who are profoundly disabled by their autism, especially those who showed apparently normal development at first, feel as the author of the article does. Their hopes as parents have been dashed. Hopefully, they will come to appreciate their child once their disappointment and grief is addressed.

I have some sympathy for people with views like those in the article but personally I don't agree with much of it.

A4 members have a very wide spectrum of opinions around ASD. The article reflects views on the spectrum. I appreciate hearing your views as well. Thank you for your input.

Regards
Bob Buckley

I don't understand the purpose of reprinting the Dan Olmstead article, "The Age of Autism: What epidemic?" The article is of no value in contributing to knowledge of autism. It relies on emotive and inaccurate rhetoric to prove nothing at all. In addition, likening autistic people to cancer, doubting their existence and trivialising their experiences are discriminatory. I doubt that calling any other minority group "an epidemic" would be tolerated, particularly in a situation where members might logically expect to be understood and respected. There are many articles which could contribute to meaningful debate without demeaning autistics.

Yours sincerely
Geraldine Robertson

Dear Bob,

In a recent episode of the nine network series "Without a Trace", there was an excellent portrayal of a family of a 12 year old child with autism that went missing. In this episode the child was wearing a tracking device on his wrist like a watch. I thought what an excellent idea and set out to try and find somewhere in Australia that could supply such a device for my 6 year old autistic daughter.

My research was unsuccessful in finding an Australian supplier. Disappointed but not giving up I then searched overseas and found some information on a US supplier. They supply a project called "Project Lifesaver". This is a non-profit organization founded by police to serve police in the electronic location of wanderers in the US. What an excellent idea! This project supplies the device to families at a cost of $0-$25 per month depending on their financial situation. The applications in Australia could be numerous, not only to locate people with Autism, but also to locate people with Alzheimer's, people at risk of absconding like those on parole or house arrest.

I then contacted them to find out if they knew of any Australian suppliers or if I could obtain the device direct from them. They said that they are the only suppliers and that the device would cost $1400 plus delivery. This is more than a lot of people can afford and there are no guarantees that the device would get through customs considering it has not been tested according to Australian Safety Standards. Purchasers run the risk of it being confiscated.

My excitement has now led to frustration at not being able to purchase an item that would be crucial in ensuring my daughters safety.

Is it possible to find out if anyone else has done any research in obtaining this tracking device? Are there any police or emergency services statistics on resources used in locating special needs, Alzheimer's or even people on parole or house arrest? Has anyone any information that could lead to a similar project being started in Australia?

Regards
Gina Cecala

Following my previous email I thought you might find these website addresses helpful www.caretrak.com/lifesaver/lifesaver.php <http://www.caretrak.com/lifesaver/lifesaver.php> & www.caretrak.com/lifesaver/facts.php <http://www.caretrak.com/lifesaver/facts.php>

Gina Cecala

Attached you will also find the governments response to Caroline Cristina

A4 Contacts

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A4 Convenor, Bob Buckley
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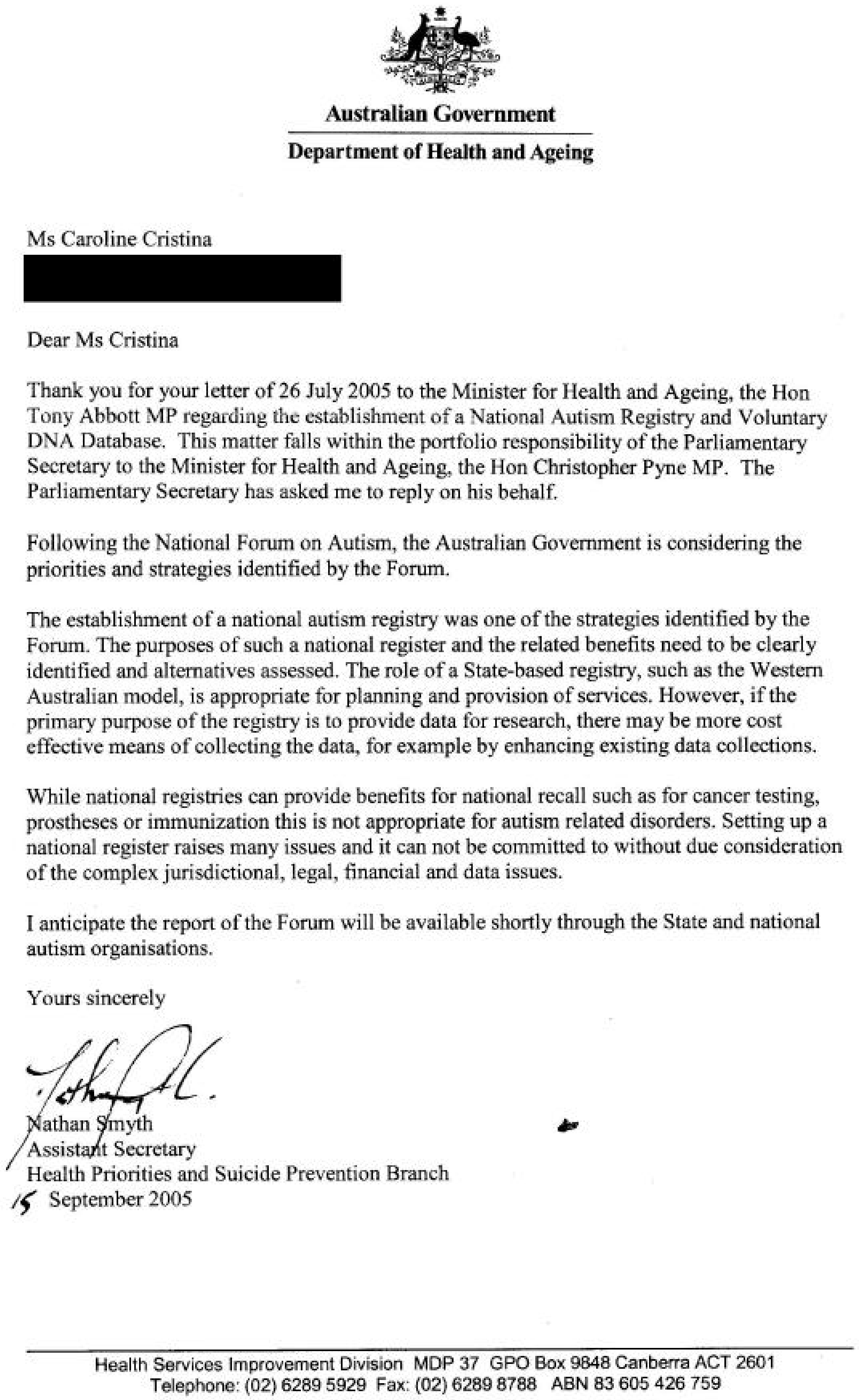

Australian Government

Department of Health and Ageing

Ms Caroline Cristina
[redacted]

Dear Ms Cristina

Thank you for your letter of 26 July 2005 to the Minister for Health and Ageing, the Hon Tony Abbott MP regarding the establishment of a National Autism Registry and Voluntary DNA Database. This matter falls within the portfolio responsibility of the Parliamentary Secretary to the Minister for Health and Ageing, the Hon Christopher Pyne MP. The Parliamentary Secretary has asked me to reply on his behalf.

Following the National Forum on Autism, the Australian Government is considering the priorities and strategies identified by the Forum.

The establishment of a national autism registry was one of the strategies identified by the Forum. The purposes of such a national register and the related benefits need to be clearly identified and alternatives assessed. The role of a State-based registry, such as the Western Australian model, is appropriate for planning and provision of services. However, if the primary purpose of the registry is to provide data for research, there may be more cost effective means of collecting the data, for example by enhancing existing data collections.

While national registries can provide benefits for national recall such as for cancer testing, prostheses or immunization this is not appropriate for autism related disorders. Setting up a national register raises many issues and it can not be committed to without due consideration of the complex jurisdictional, legal, financial and data issues.

I anticipate the report of the Forum will be available shortly through the State and national autism organisations.

Yours sincerely

Nathan Smyth
Assistant Secretary
Health Priorities and Suicide Prevention Branch
15 September 2005

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