



UPDATE

Autism Aspergers Advocacy Australia

September 2007

Issue 5

Be active for ASD

From A4's Steering Committee

People with autism spectrum disorders need you to act.

Please, please send your political candidates a message.

Sending a simple message to leaders of the main political parties is easy. Their websites are:

- <http://www.pm.gov.au/contact/index.cfm> and click on continue
- <http://www.kevin07.com.au/your-say/your-say/your-say.html>

A simple message (feel free to change this any way you want) to the political leaders is:

People with autism spectrum disorders (ASD) need ASD-specific services and support. Generic disability services do not meet their needs. No more delays! People with ASD need action from the federal government now.

Please make sure you mention 'autism spectrum disorders' or just 'autism'.

Please do more if you can. For example, write to candidates in your electorate. Use the website <http://apps.aec.gov.au/esearch/> to find your federal electorate. Type in your suburb or postcode and it will tell you the name of your electorate.

To find the Liberal candidates, you can go to the Liberal website <http://www.liberal.org.au/> then on the left, choose your state. Most state websites list their candidates for each electorate and their candidates for the Senate. The Liberal candidates who want your vote and who may end up representing you in the federal parliament are:

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- candidates for your federal electorate.
- Senate candidates for your state or territory.

For Labor/ALP candidates, go to the website <http://www.alp.org.au/people/index.php>. The websites provide contact information for each candidate.

If you have specific issues that you want to raise, why not raise them with the existing ministers and shadow ministers? You can send messages to the following politicians:

<p>The Hon. Mal Brough MP Minister for Families, Community Services and Indigenous Affairs Mal.Brough.MP@aph.gov.au http://www.aph.gov.au/house/members/memberfeedback.asp?id=2K6</p> <p>Senator Nigel Scullion Minister for Community Services senator.scullion@aph.gov.au</p>	<p>The Hon Jenny Macklin MP Shadow Minister for Families & Community Services JMacklin.MP@aph.gov.au</p> <p>The Hon Tanya Plibersek MP Shadow Minister for Human Services tanya@tanyaplibersek.com http://www.aph.gov.au/house/members/memberfeedback.asp?id=83M</p>
<p>The Hon. Tony Abbott MP Minister for Health and Ageing Tony.Abbott.MP@aph.gov.au http://www.aph.gov.au/house/members/memberfeedback.asp?id=EZ5</p> <p>Senator Brett Mason Parliamentary Secretary for Health senator.mason@aph.gov.au</p>	<p>The Hon Nicola Roxon MP Shadow Minister for Health nicola.roxon.mp@aph.gov.au</p> <p>Senator Jan McLucas Shadow Minister for Ageing, Disabilities and Carers senator.mclucas@aph.gov.au</p>
<p>The Hon Julie Bishop MP Minister for Education, Science and Training julie.bishop@dest.gov.au</p>	<p>The Hon Stephen Smith MP Shadow Minister for Education & Training Stephen.Smith.MP@aph.gov.au</p>
<p>The Hon Joe Hockey MP Minister for Employment and Workplace Relations J.Hockey.MP@aph.gov.au</p>	<p>The Hon Julia Gillard MP Shadow Minister for Employment & Industrial Relations, Social Inclusion Julia.Gillard.MP@aph.gov.au</p>
<p>The Hon Phillip Ruddock MP Attorney General http://www.aph.gov.au/house/members/memberfeedback.asp?id=0J4</p>	<p>Senator Joseph Ludwig Shadow Attorney General senator.ludwig@aph.gov.au http://www.aph.gov.au/Senate/senators/homopages/contact.asp?id=84N</p>
<p>The Hon Mark Vaile MP Leader of The Nationals http://www.markvaile.com.au/contacts.asp http://www.aph.gov.au/house/members/memberfeedback.asp?id=SU5</p>	<p>Senator Bob Brown Leader of the Australian Greens senator.bob.brown@aph.gov.au</p>
<p>Senator Lyn Allison Leader of the Australian Democrats senator.allison@aph.gov.au</p>	<p>Senator Steve Fielding Leader of the Family First Party senator.fielding@aph.gov.au</p>

Write short messages with one or two points. Do not ask questions as you will not get useful answers. Just tell them what you want. If you complain make sure you offer a solution (or just ask for immediate action ... they've have already been told repeatedly what they need to do). You can send multiple messages if you like — send them a few days apart, or weekly. Tell your friends and relatives, if they want to help then they can send messages about autism spectrum disorders to politicians as well.

If you are not sure what to write, here are some suggestions for relatively short messages.

- Messages for both Mr Howard and Mr Rudd— click [here](#).
- Messages just for Mr Howard — click [here](#)
- Messages just for Mr Rudd — click [here](#).
- All the messages, in one go — click [here](#).

WA Criteria for Successful Inclusion

The Western Australia Education Department's ASD Units use the following list to assess a child's readiness for mainstreaming.

CRITERIA FOR SUCCESSFUL INCLUSION

LANGUAGE SKILLS

- Follows two-step directions when presented to a group
- Communicates needs and desires
- Answers and asks simple questions
- Engages in simple exchanges of conversation
- Recalls experiences

SOCIAL SKILLS

- Takes turns
- Waits quietly
- Reciprocates greetings from adults and peers
- Participates in mat/circle activities
- Initiates play activities with peers
- With/without adult prompts
- Imitates peer play

BEHAVIOUR SKILLS

- Responds to delayed contingencies at end of session, at end of day
- Exhibits disruptive behaviour at near zero levels in all environments
- Stereotypic behaviours are under stimulus control ie: in own room, not at school

ACADEMIC SKILLS

- Learns by watching others
- Completes seat work independently
- Raises hand to seek teacher attention
- Learns targeted objectives during group instruction
- Completes academic curricula at similar rate to age peers

I was emailed this list from the Education Department's Program Coordinator for ASD Schooling Units. I wanted to discuss how readiness for mainstreaming is determined and what provisions are if my son is not yet ready, as he is due to start in mainstream next year.

The discussion was not overly encouraging. I was told in WA the Pre Primary year is not compulsory so I can keep him home for the 50% of the time he is not able to access the Education Support Unit (i.e. home school him). Then she emailed me the attached list to help me determine if my son is ready for mainstream. Well, he does not meet any of this criteria at all so what was I to think?

I subsequently sent this list out to a group of parents in WA and I have never seen such overwhelming response, most parents think that this list is so far off the mark for determining readiness for mainstreaming and should be considered more of an ideal list and goals for the future. So many parents emailed me their story regarding how they have managed mainstreaming and the Education Department and provided helpful and reassuring advice.

I felt very sad when I read this list as I cannot say my son would successfully meet any of the criteria. Once others read it they also told me how most of their children would not meet very much of this criteria either; yet have had a great deal of success in mainstream schooling.

Janet
4/9/2007

Convenor's comment:

Does your state have criteria for mainstream inclusion? If so, please let me know.

Parents can use this list as a basis for program goals in early childhood. Will your child's program ensure your child achieves these developmental goals by the time he/she reaches school age? If not, is your state ensuring children get the treatment, rehabilitation and education that is their right? Now is a good time for people to review individual programs and consider their child's placement next year.

Subsequent email

From: BRIGG John [Inclusive Education Standards] [mailto:John.BRIGG@det.wa.edu.au]

Sent: Friday, 7 September 2007 8:19 AM

The list [above] CRITERIA FOR SUCCESSFUL INCLUSION is not an official document of the Department of Education and Training (WA) the Centre for Inclusive Schooling or the Department's Autism Units. The document therefore has no status within the Department. It is not a policy document and is not used by any Department school psychologists or visiting teachers to decide if a child should attend his/her local school. This decision is ultimately the parents.

The list has been derived from the USA where in some of their systems and programs they have very clear criteria for transition from intensive intervention programs to local schools. They do this because they believe there is clear evidence that indicates unless the child has these skills the chances of success at the local school are significantly reduced.

Let me say again, we do not apply these criteria in public schools in Western Australia. However in the Autism Units (for kindergarten and pre-primary aged children with Autism) the criteria are used as a guide in relation to what teachers, education assistants and parents are working towards; an ideal, if you like. There is absolutely no sense that children will not transition completely to Year 1 at their local school if they do not reach all the criteria. Children do not repeat the pre-primary year in the Autism Units – they all move on to fulltime in Year 1 at their local school.

I hope this clarifies things for your members or interested parents.

Best wishes

John Brigg

MANAGER, INCLUSIVE EDUCATION

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Article on Mercury and Autism

Keri Waldron

There is a growing consensus among the DAN (founded by the late Dr Bernard Rimland) and Pfeiffer "biological treatment of Autism" fraternity that a majority of the recent decades Autism epidemic is probably a result of an initial toxic exposure in infancy to mercury (along with other environmental dangers like lead, arsenic, PCBs etc.)

Joseph Mercola MD publishes a web based health newsletter, read widely, including most up to date alternate health lifestyle treatments for cancer, heart disease, Chronic Fatigue etc. etc.- i.e. the major diseases of modern times.

His recent article on autism is at this link —

<http://articles.mercola.com/sites/articles/archive/2007/08/14/mercury-contamination-is-destroying-public-health-and-spawning-an-autism-epidemic.aspx>

Convenor's message

Dear A4 member

The federal election looms. I aim to make it as easy as possible for you to have your say. Please act now for the sake of people with ASD. Please email me (cnvnr@a4.org.au) with your questions, suggestions or advice.

Some key politicians and bureaucrats, at both federal and state level, oppose government providing essential services for people with ASD. I continue to get reports of key people saying "if we help people with autism, then we have to help everyone". Civilization involves helping community members who need help. A purpose of government is to ensure people who need help get it.

Typically, these people support treatment for most other clinical conditions affecting children but oppose funding treatment for autism spectrum disorders. Personally, I find prejudice like this among key political decision makers especially distressing.

Despite this, I see a glimmer of hope: signs that some Liberal politicians and a few senior bureaucrats have dawning recognition of the needs of people with ASD. I feel the ALP remains asleep with just the barest signs of interest. And there are strong opponents on both main political parties who will easily block our progress.

Now is the time to increase pressure and get some action. Please, do what you can to progress the cause of people with ASD. If you have never written to or spoken with a politician or political candidate, now is the time to do it. If you have not done it for a while, please do it again.

Please tell the candidates in the coming election what is important to you; don't just copy what I say. Make sure you mention "autism spectrum disorders" (they will not recognize ASD). It is good to mention Aspergers or PDD ... but mention "autism spectrum disorders" as well. Keep your message short and simple.

Thank you in advance for your efforts.

Federal Ministers Responsible for Autism

Previously, I reported that I wrote to the Prime Minister, Mr Howard MP, about issues relating to the responsibilities of various federal Ministers and their Departments (see www.a4.org.au/documents/JH061215-A4.doc). Copies of the letter were sent to all the relevant Ministers for their individual comment.

Having not received a response from any of the relevant Ministers or their Departments,

- I contacted Senator Humphries who followed up the Prime Minister's office, and
- I used the Freedom of Information process to see what each Minister did with the email I wrote to them raising concerns and with their copy of the letter I sent to John Howard.

Two meetings with Government

Eventually, the Prime Minister wrote back on the 9/6/2007 (see <http://www.a4.org.au/documents/JH070609.pdf>) saying:

Dear Mr Buckley

Thank you for your letter of 15 December 2006 regarding federal government Assistance and services for people with autism spectrum disorder. I apologise for the delay in replying.

I note your view that the responsibility for matters relating to people with autism should not be held by a single government department. Given the need for a whole-of-government approach. I have decided to maintain the current arrangements where autism-related programmes, policies and services are the responsibility of relevant government departments.

I have also asked individual ministers to ensure that senior officials from their respective departments meet with you to discuss the particular issues raised in your correspondence.

Despite instructions from the Prime Minister, none of the Ministers nor their senior officials contacted me. Eventually and with urging from ACT Senator Gary Humphries, the Department of Prime Minister and Cabinet (PM&C) contacted me. Since then I have attended two meetings organized and run by PM&C.

The first meeting involved senior officials from the mental health section of the Department of Health and Ageing (DoHA), and the disability section of Family and Community Services and Indigenous Affairs (FaCSIA). I spoke about the need for

- comprehensive clinical services that contribute to a broad range of early interventions, treatments and rehabilitation
- much improved ASD awareness and expertise across the health sector, and
- disability services and supports that recognize the distinct nature and challenges that confront people with ASD and their families/carers.

They gave me very little information in return. At the end of the meeting I asked what I could tell A4 members about the meeting. They said I could “tell A4 members that the meeting occurred”.

The second meeting was with officials from the Attorney General’s Department and the Department of Education, Science and Training (DEST).

A human rights lawyer from the Attorney General’s Department had quite a bit to say about the Government’s official position on how Human Rights are protected in Australia.

The person from the Prime Minister’s Department told me that the legal system was unlikely to ever be a solution, and wondered why parents would ever try to use the legal system.

The discussion was quite intense. Frankly, my experience and the evidence clearly show many of the rights of people with ASD most depend on are not protected and are routinely denied. I said that the media and politicians, who Mr Howard (Prime Minister) says protect Human Rights in Australia, have been profoundly disinterested in the rights of children with ASD to effective treatment, education, etc. They are not prepared to ensure Australian legal systems are fair and/or timely. Clearly, the rights of Australians with ASD are not protected.

I described how the legal systems in Canada and the United Kingdom also fail, but that federal laws like the **Individuals with Disabilities Education Act (IDEA)** (see http://en.wikipedia.org/wiki/Individuals_with_Disabilities_Education_Act and <http://www.wrightslaw.com/idea/>) in the United States have been a more effective means to protect the right to some essential services and an improved quality of life.

As I understand it, the Australian Government protects its right to choose how it spends its money (once called tax-payer’s money): choosing to ignore the needs of children for essential treatment for their autism. This choice maximizes the suffering of people who are profoundly impacted by their untreated ASD and subjugates their families. The Government’s laws prevent people from mounting legal challenges to its decisions and conduct relating to children with ASD.

I expect to continue this discussion with the Government. I am preparing a detailed response/commentary to the advice (misinformation?) that the Attorney-general’s Department recently provided to PM&C.

The representative from DEST did not get a word in.

Freedom of Information (Fol) request

Last Update, I said

I wrote a series of Freedom of Information requests asking for all the information and documents relating to and arising from my letters. Maybe we can find out what the Ministers and their departments do with our letters.

The following describes the results so far.

The Department of Health and Ageing insisted I pay \$30 before they would even consider whether the \$30 fee would be waived. A month later, they wrote me a letter saying they decided to waive the fee and will try to send the \$30 back to me. All the others managed to waive the fee on the basis of the information provided in my original request.

The initial response (31/7) from Freedom of Information officer in the Department of Employment and Workplace Relations said:

I have caused searches of the Department's Ministerial correspondence records to be undertaken, as well as searches by those Branches of the Department which may have been referred your letter. The Department has also made inquiries of the Minister's office. I am advised that neither the Department nor the Minister's office have any record of receiving your letter of December 2006, nor any letter from A4 Autism Aspergers Advocacy Australia in the recent past. Accordingly, it seems unlikely that the Department would have any documents relevant to your request.

I wrote back saying

Thank you for your email (31/7/2007)

Below is the email I sent to Kevin Andrews MP, who I understand was the Minister responsible for DEWR at the time. As you can see copies were sent to several other Ministers in exactly the same email. None of these emails bounced. I understand this means all these messages arrived at their destinations.

I would like to know what happened to the email sent to Kevin Andrews MP in relation to DEWR's role and responsibilities for people with autism spectrum disorders.

I don't know whether the attached information would help in finding relevant records. If you are confident that the Minister's office has no record of receiving our letter, I will accept your email as formal notification that the Minister's office failed to record receiving this letter and that the important issues it raised with the Minister were not considered.

The FoI officer responded (9/8) saying ...

Dear Mr Buckley,

Thank you for your e-mail of 1 August 2007, enclosing a copy of your e-mail of 20 December 2006 to Minister Andrews, then Minister for Employment and Workplace Relations.

A search by Minister Andrews' staff of his e-mail account has revealed that your e-mail was received on 20 December 2006. Unfortunately, it was not actioned at that time. The Minister's office sincerely apologises for this oversight.

Your e-mail and its attached letter to the Prime Minister has now been entered into the Department's system for managing Ministerial correspondence, and you will receive a response to it shortly.

The response from DEST (17/8, click [here](#) to download) said:

The Department of Education, Science and Training does not hold any of the documents you seek, which relate to an area outside the Department's portfolio responsibilities.

I felt this was not an appropriate response from the Department whose responsibilities include Education. I wrote back (18/8), and copied a senior staffer in the Prime Minister's Department, saying:

Thank you for your letter (17 August 2007) relating to my request made under the *Freedom of Information Act 1982*. In your letter you state:

The Department of Education, Science and Training does not hold any of the documents you seek, which relate to an area outside the Department's portfolio responsibilities.

Please would you confirm that:

1. the Minister's Office discarded the email from Autism Aspergers Advocacy Australia (A4) and the letter it contained (as described in my FoI request) without making any record of having received it or responding to their contents in any way.

2. neither the Minister for Education, Science and Training nor your Department received any communication from the Prime Minister or his Department arising directly from A4's letter that included issues relating to the education of children with autism spectrum disorders.
3. neither the Minister's Office nor the Department of Education, Science and Training received a copy of the letter that the Prime Minister John Howard sent to Tony Abbott on the 9th June 2007, relating to the contents of the email above ... in which Mr Howard said:

"Given the spread of responsibility across portfolios, it is essential that all departments share information and work collaboratively in response to autism-related issues, ensuring good policy outcomes for autism sufferers, their families and carers. More open inter-departmental cooperation will enable stakeholders concerns on this sensitive matter to be more consistently and effectively addressed. I ask that senior departmental officials from the Departments of Health and Ageing; Families, Community Services and Indigenous Affairs; and Education, Science and Training meet with the autism advocacy body, A4, to discuss their issues of concern.

"This letter has been copied to the Minister for Families, Community Services and Indigenous Affairs and the Minister for Education, Science and Training."

In particular, please confirm that the Prime Minister did not send the copy of the letter to the Minister for Education, Science and Training as described immediately above.

4. in the views of the Minister for Education, Science and Training and your Department (contrary to the view of the Prime Minister stated above) all issues relating to children with autism spectrum disorders, including their education, are
 - a. entirely "an area outside the Department's portfolio responsibilities"; and
 - b. primarily a responsibility of the Department of Health and Ageing.

As yet, DEST has not responded to this email.

So far, the Attorney-General's Department is the only Department that responded appropriately to my FoI request. They provided documents showing that back in March the AG's Department started to prepare a "standard response" to the issues A4 raised for the Prime Minister's Department. But it seems activity just stopped.

A copy of the eventual response (dated 27/8) from the Attorney-General's Department was given to me at the meeting organized by the Prime Minister's Department (click [here](#) to view it) on 30/8 (see above).

Hopefully, there will be ongoing discussion over the rights of people with ASD. Getting the federal Government to protect the rights of people with ASD is a massive political battle. Australian Governments vigorously resist any external scrutiny of their decisions, especially of their decisions to not act.

Responses to my FoI requests from the following Ministers' Offices and their respective Departments are now overdue.

- The Prime Minister
- Department of Health and Ageing
- Family and Community Services, and Indigenous Affairs
- Department of Education, Science and Training

Clearly, Government officials consider people with ASD and their national representatives unimportant. They ignore legal requirements to respond in given timeframes ... though they impose harsh penalties on members of the public who behave in such a manner. So much for the [ethics of reciprocity](#) and "Do unto others as you would have them do unto you." [Jesus (c. 5 B.C. - A.D. 32) in the [Gospels](#), [Matthew 7:12](#), [Matthew 22:39](#), [Luke 6:31](#), [Luke 10:27](#)].

Regards
Bob Buckley
8/9/2007

P.S. I received a response from the Department of Health and Ageing, but most of the relevant information was deemed irrelevant ... and not provided.

Members of the Labor Party are far too busy to meet ASD representatives, or even just talk to us on the telephone. After numerous requests for meetings, an opposition advisor finally met two autism representatives simultaneously. We expected to meet two or three advisors but only one turned up. He was new and was still learning. We provided as much information as we could in the time. The advisor could not make any commitment.

If you are interested in human rights for people with ASD, my commentary on the letter from the Attorney General's Department to PM&C can be downloaded from <http://www.a4.org.au/documents/PMC070906HRpublic.doc>. If you can comment with any expertise or just feel a desire to do so, feedback on this issue would be greatly appreciated.

ASD in the media

Bob Buckley

The most depressing story for some time comes from Tasmania: see *Mum's cry for help* (<http://www.news.com.au/mercury/story/0,22884,22371788-5007221,00.html>) from the Mercury. It was also mentioned on Channel 7's Sunrise program. I urge all A4 members to send this story, or a link to it, to every federal political candidate that you can. Ask Governments to stop neglecting our most vulnerable citizens at both federal and state levels. Please ask your friends and families to write to their candidates.

Congratulations to Autism Awareness (see <http://autismawareness.com.au/>) who got a 7 page story in the latest Woman's Weekly (starting on page 168). Autism Awareness also got their story on television. Click [here](#) to view the video.

Congratulations to A4 member Janet McLean for her role in recent publicity in Western Australia. She is involved in a Stateline story (see <http://www.abc.net.au/stateline/wa/content/2006/s2016647.htm>) that discusses the ongoing failure of federal and state governments to address the needs of people with a disability.

One of the best written newspaper stories I've seen on autism/ASD in quite a while appears in The Times in the UK. It is called "*Hunting the gene that traps children in their own world*". To read it, click [here](#).

The ABC's Compass program did a story call *A Week with William*. It is about the family and supporters of a youth with autism and other challenges. The transcript is at <http://www.abc.net.au/compass/s2028328.htm>

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.

Update team: editor-at-a4.org.au

Editing: normally Juanita and Vicki ... but Bob Buckley did this one.

Reporting: vacancies in all states.

Production: Helen Curtin – proof-reading (Qld), Bob Buckley – distribution (ACT).

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