



Dear A4 members

This is my first A4 Update. It will be a while before I can whip these together as well as Judy did so please bear with me.

The A4 website at www.a4.org.au is up and running. We had an online opening ceremony “attended” by a small number of people who were widely distributed around the country. The short formal proceedings flowed into an informal “get together” that ended up extending late into the evening.

The last few months have been busy all around the country.

- Both Tasmania and the ACT held highly successful conferences.
- More recently, I sent a submission to the Standing Committee on Family and Community Affairs on behalf of A4.
- I spoke with the Productivity Commission Inquiry into the Commonwealth Disability Discrimination ACT, both as an individual and as Convenor of A4. Some of our points are the same as or similar to points made by the ACT Human Rights Office and the HREOC’s submission to the Inquiry.

Recently autism/ASD received significant attention in federal parliament. This provides an opportunity for you to make a difference. My first request to you, the A4 membership, is to ask you to thank the politicians who have spoken on our behalf. We can’t go into parliament and make our own arguments. We need the support of people in parliament. If we let our parliamentary representatives know that we are listening and that we appreciate them highlighting our concerns in public and in parliament, they will continue to do so.

regards

Bob Buckley — Convenor

June 2003

A4 Member's Activity: write to a politician

A4 asks you, the individual A4 members, to act. We want each of you to write a very short letter to a federal politician. At present there are four especially worthy politicians to choose from.

Recently, four federal politicians spoke about autism in the Australian Parliament. A4 Update No. 5 2003, the previous newsletter, quoted Sue Knowles' speech. Please take a look at what the other politicians said: the A4 website has extracts from Hansard showing the other significant mentions of autism/ASD (the URL is www.a4.org.au/asd_in_parliament.htm).

A4 asks each member to write to one of these politicians to thank them for their support. Choose a politician: either one from your own state, the one you like the most or the one whose speech you like best. The aim of this A4 activity is to show strong appreciation and to encourage more support for autism in parliament. We also ask that you let us know who you wrote to by filling in the online form on the website. The A4 form is on the 'survey' page at www.a4.org.au/surveys.htm.

Please write a very simple letter to one of the politicians. You should include:

- your address
- then 'Dear ...' followed by
- one paragraph saying thanks for raising autism/ASD as an issue
- 'your truly' or whatever you prefer
- your signature and your full name
- the date of the letter

Politicians have two addresses: their electorate office and their parliamentary office. You can send your letter to either address. You can send it by email, but it would be better to post your letter. Here are their addresses:

Senator Susan Knowles senator.knowles@aph.gov.au House of Representatives Parliament House Canberra ACT 2600	Liberal Party of Australia PO Box 930 West Perth WA 6872
Senator Natasha Stott Despoja senator.stottdespoja@aph.gov.au House of Representatives Parliament House Canberra ACT 2600	Australian Democrats PO Box 3419 Rundle Mall SA 5000
Mrs Kay Hull MP Kay.Hull.MP@aph.gov.au House of Representatives Parliament House Canberra ACT 2600	National Party of Australia 28 Baylis Street Wagga Wagga NSW 2650

Mr Anthony Byrne MP Anthony.Byrne.MP@aph.gov.au House of Representatives Parliament House Canberra ACT 2600	Australian Labor Party PO Box 1076 Dandenong Vic 3175
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One of our members pointed out that Pat Farmer, former long-distance runner and athlete, raised money for autism before entering parliament. He is now the Member for Macarthur (southwest of Sydney and the southern highlands).

A4 website

Since its launch, the A4 website has received very positive feedback. The feedback has been a great morale boost for those involved.

There are two parts of the website that I would like to highlight. The online membership form and the forum on the feedback page.

Online membership form

We'd like to encourage people to use the online membership form rather than any other way to let us know you are interested. Please use the form to keep us informed of your email address or other personal information.

Please let others know about the online form.

There are several people who sent forms but we have not been able to get their email address right. We simply have not had time or resources to follow-up. If you know someone like this, please ask them to use the electronic form.

Forum

The forum on the Feedback page of the website is an opportunity for A4 members to raise issues and to comment on the issues raised. This is a simple means for A4 members to be involved.

Government Inquiries

Improving Children's Health and well-being

The Standing Committee on Family and Community Affairs is currently conducting an [Inquiry into improving children's health and well being](#). A4 recently sent a submission to the Inquiry. Thanks to all those who helped prepare the submission.

A4 is aware of the following submissions to this inquiry that relate specifically to autism/ASD. Only the first of these submissions is available on the Inquiry's submission page at this time.

- submission #5 from [Mr Peter Kiefel & Mrs Wendy Kiefel](#)
- a submission from Autism Behavioural Intervention Coalition, a loose coalition of state ABA groups.
- the submission from A4 (submission in [Word](#) or [PDF](#) and Annex 1 in [Word](#) and in [PDF](#)).

Productivity Commission Inquiry into the DDA

The Productivity Commission is conducting an inquiry into the Disability Discrimination Act (DDA). While a number of submissions mention autism (No.s 28, 44, 74, 86,91, 99 and 104) or Aspergers (No.s 28, 115), only a few are focussed on ASD. Two parents of children with autism made individual submissions to the inquiry:

- submission 28 from Hilary Royes ([sub028.rtf](#) or [sub028.pdf](#))
- submission 104 from Bob Buckley ([sub104.zip](#) or [sub104.pdf](#))

Bob Buckley spoke to the Inquiry when it was in Canberra, both as an individual and on behalf of A4. The Productivity Commission inquiry is due to report in April next year.

What the MOW said ...

Newspapers around the country recently printed a story on autism diagnosis by an anonymous AAP reporter. The story said:

Children are being falsely labelled as autistic so their parents can qualify for government funding, according to a report.

The GP newspaper Medical Observer Weekly says doctors are coming under pressure to diagnose autism spectrum disorder in children with a range of behaviour and learning difficulties so desperate parents can access assistance with care and schooling.

The popular press seems happy to print claims that paediatricians around the country, under pressure from “desperate parents”, are engaging in widespread medical fraud. The following article was in the Medical Observer Weekly.

Autism labels ‘overused’ to gain funding

by Rada Rouse

CHILDREN are receiving “unnecessary labels” with autistic spectrum disorder (ASD) diagnoses so they can access government funding for care and schooling, paediatricians say.

Children with multiple behavioural, socialisation and learning difficulties but no label do not qualify for support, leading to pressure on clinicians, it has been claimed.

“If a case is borderline, you’re inclined to make the diagnosis because you’re interested in helping the families,” Perth developmental paediatrician Dr John Wray said. “It’s a very real problem.”

Dr Wray, from the State Child Development Centre at Princess Margaret Hospital, said a workshop at the Royal Australasian College of Physicians (RACP) recent annual conference called for

national consensus on ASD diagnostic criteria.

Best practice involved the use of multidisciplinary teams – involving a paediatrician or psychiatrist plus speech pathologist and psychologist – to assess a child for ASD, but in some Australian states a single paediatrician or psychologist could make the diagnosis.

Dr Natalie Silove, consultant neurodevelopmental paediatrician at The Children’s Hospital, Westmead, said that clinicians were loath to give a child a diagnosis such as Asperger’s syndrome which had a “dreadful prognosis”, but there was no gold standard.

“A lot of paediatricians prefer to describe a child rather than label them; however, that doesn’t do it for the education department, so they are forced to give a label for a specific diagnosis ... it’s a dilemma.”

No-one knows whether the increase in ASD incidence is real, a reflection of broader diagnostic criteria, or partly driven by the availability of government funds.

Dr Clare Cunningham, director of the developmental assessment unit at Sydney Children’s Hospital, Randwick, said the clinic was seeing an increasing number of referrals from schools where funding “might well be the underlying motivation”.

Victorian paediatrician Associate Professor Peter Hewson, from Barwon Health, said global estimates of ASD prevalence as high as 1 in 100 may indicate unwarranted medicalisation of children’s behaviour. A new study of children with ASD in Barwon showed an incidence of 1 in 250, whereas it was estimated at 1 in 1000 only a few years ago.

Paediatrician Dr Adam Buckmaster from Gosford, NSW, said children diagnosed with Asperger’s syndrome were eligible for state education department assistance.

“Say you have a child with borderline intellectual disability plus ADHD plus some oppositional defiance – in other words a nightmare child – you don’t get any funding,” he said. “Most paediatricians want to help the parents and if you can just bend a little bit, most paediatricians will do that.”

The MOW article does not explain why increased diagnosis deserves to be called ‘overuse’. Or how a diagnosis is an ‘unnecessary label’ when the label is required to assess essential services like an effective education. This article states best practice for ASD diagnosis involves a multidisciplinary team. It clearly identifies “an increasing number of referrals from schools where funding ‘might well be the underlying motivation’”.

The professionals quoted in this article indicate their perception that government agencies increasingly require a formal diagnosis in order that children receive the support that they need. It seems quite likely that a part, perhaps a significant part, of the increasing diagnosis rate for Autism Spectrum Disorders is due to increasing demands by government agencies and services providers for a clinical diagnosis in order that a child be provided with non-clinical services, or even have their needs recognised.

It is disappointing that elements of the community are keen to blame the behaviour of parents for autism and related issues. In this case, referrals from education professionals at the coalface are increasing, but again parents get the blame for autism.

MJA website

The Medical Journal of Australia is at www.mja.com.au. You might be interested in searching the website for autism (14 mentions), Aspergers (no mention) and PDD or PDD-NOS (1 mention, also mentions autism).

Last year, Bruce Tonge wrote [Autism, autistic spectrum and the need for better definition](#).

The most recent article, an editorial entitled [Children with autism deserve evidence-based intervention](#), advocates Applied Behaviour Analysis on the basis of available evidence for children with autistic disorder (sometimes called classic autism).

Conferences

The ACT Conference was a great event. It provided a mixture of presentations. There were papers from professionals and researchers, presentations from government agencies and we heard from politicians at both state and federal level. The conference was well attended.

Initial reports from Tasmania suggest their conference was extremely good. Attendance was spectacular. One person wrote “For me, the highlights of the conference were:

- Having the opportunity to meet with other Tasmanians who have Aspergers in the peace of an autism retreat room.
- Listening to Vicki Bitsika emphasise that the DSM IV has got it wrong, as AS adults have been saying for yonks.
- Listening to Vicki describe how it is not the IQ scores that show autistic thinking, but the way people do the test and the reasoning behind the

responses. That is also something AS people have been saying for yonks.

- Ben Gardner (age 20) and Alex Hodge (age 18) both spoke very well. A parent asked if she should tell her 9 year old that he has AS. Both young men were emphatic that they are glad that their parents told them when they were young, even though at the time, they were not interested in autism.
- Judy's speech at dinner, because it has so much in common with the experiences so many parents express. Apart from that, it was an excellent speech, because she is not afraid of honesty and will say things that need to be said.”

SPOUSE SUPPORT GROUP

For Partners of Adults with Asperger's Syndrome

Mutual understanding and acknowledgement of the Asperger marriage experience, as well as information, contacts and support. Attention will also be given to finding ways to increase community & professional awareness of Asperger's Syndrome in marriage.

1st Saturday of every month, 2pm – 5pm.

Parramatta RSL Club, Lachlan Room

Cnr Macquarie & O'Connell Streets, Parramatta

Free parking Macquarie St, opposite RSL entrance

GRASP Co-ordinator: Carol Grigg, Mobile: 0408 817 828; Email: cgrigg@bigpond.net.au; Postal: PO Box 129, YAGOONA NSW 2199