

AUTISM ASPERGERS ADVOCACY AUSTRALIA - DECEMBER UPDATE

Greetings to all members of Autism Aspergers Advocacy Australia (A⁴), and thank you for your support in joining our new organisation.

Together, we hope to make a real difference to the profile and understanding of Autism Spectrum Disorder in Australia, and to influence decision making and decision makers at the national level. We know that success won't come overnight and that this we will need to stay focussed for the long term, but already there are some very positive signs

So, this email is to formally welcome you as part of our membership and to update you on what has been happening since our launch on the 12th of November, 2002.

We currently have around 300 autism families enlisted as part of A⁴ and happily the forms continue to roll in. Our aim is to be a truly grassroots organisation, representing people with autism and their families, across Australia and across the spectrum.

Melbourne International Autism Congress, November 10 – 14, 2002.

Just on 2000 delegates attended part or all of the Autism World Congress in Melbourne last month. It was a phenomenal success and congratulations to all those who organised and managed it. Particular credit to Splash Media for the amazing amount of media coverage the Congress received.

The Conference papers, and tapes of the sessions are available, as well as a lot of additional information, on the website at www.autismcongress.com. Make sure that you check out the Communique that was issued at the end of the Congress, it contains an overview of the Congress and lists the main issues that arose.

A4 Steering Committee

From the A4 Launch at the Congress, a steering committee of 22 people has been formed to co-ordinate Autism Aspergers Advocacy Australia's activities. The steering committee is very inclusive and representative. It has representation from all States and from the ACT (a volunteer from the NT is welcome) and it comprises people with ASD and families of people with ASD, as well as professionals. It covers different age groupings and interests, and so should be able to feed in the priorities of people with ASD across the spectrum.

The steering committee has been emailing regularly and plans a first face to face meeting in Melbourne on 9 February next year. The key discussion points for this meeting will be the co-ordination of the Canberra advocacy event in June, priority setting for Federal issues, and various promotional activities.

Policies and Priorities

Members of the A4 Steering Committee have been working on a number of policy discussion papers and these will be circulated for comment to the A4 membership in January. Topics include: Vocational training, the effectiveness of Case Managers and Australian ASD incidence rates.

If you have a paper on an issue that relates to the national agenda for ASD that you would like considered for adoption by A4, please send it to me at aaadvocacy@bigpond.com. The issue must be something under the primary jurisdiction of the Federal Government.

Promotional

We are currently working on a range of promotional material for A4 so that we can represent our membership in a professional and effective way. One of our A4 members has very kindly volunteered their services to produce an A4 promotional video, and work on this has already commenced. There is also the possibility of some community service announcement being produced for us to be aired initially on the Melbourne and Sydney Community TV Channels.

One of the issues earmarked for discussion at the February Steering Committee meeting is the ongoing maintenance and upgrading of our website.

Media

The Autism Congress has created an excellent environment for increased media exposure of ASD issues, and we have been following this through with some good print media stories and features. We encourage you to work at this in your local area and with your local media outlets. Letters to the Editor are an easy place to start, or calls to talkback radio. It is amazing how successful you can be if you try.

One of our members - "just a Mum" - recently wrote an article on Early Intervention and ASD, contacted the Herald Sun Editor, and found her article printed in full as an expert piece, right next to the Editorial on one of the most read pages of the highest circulation newspaper in the country. Another of our members (an integration aide) has an article on ASD about to be published in a State Teachers magazine. What have you got to lose? Next time, instead of saying how wrong it is that autism and aspergers do not receive the attention and profile they deserve, try to do something concrete about it. Most importantly, let us know how you go and we can compile a media file of ASD 'hits' – every bit helps when you are trying to put a case to government for additional support.

For action: As part of our aim to raise the profile of ASD in the community we are approaching media outlets trying to get feature stories and more detailed coverage of the needs of our families. A4 is compiling a media

volunteers file so that the next time we are approached by someone needing 6 families prepared to tell their story (as happened to us with the Womens Weekly recently) we can search through our file and match appropriate families with the geographical and demographical requirements.

If you ticked the media box on your form and are keen to follow through, please send me with the following details: Name, contact address with best daytime phone number and general location. A brief outline of your family and your involvement with ASD. It need only be a paragraph or two. Email this with Media File in the Subject Heading. This is not a commitment, just an indication that you might be available. You can always say 'no' to any specific request if it does not suit at the time.

This would also be very helpful with the filming of our promotional video. Our film producers will soon be travelling through NSW, ACT and Victoria to take footage of ASD families to include in this short production. No talking is required! Your prompt assistance with this would be greatly appreciated.

Parliament House Meetings

On 19 November Andrew Brien (ACA President) and Judy Brewer Fischer (Convenor A4) conducted a series of briefings to Members of Parliament and some advisors of key Ministers. We explained the formation of our new national advocacy group and discussed various ways in which we could work more closely with government on a range of issues.

On this visit we focussed particularly on the Family and Community Services portfolio and issues relating to FaCS. This included over half an hour with Minister Larry Anthony, Minister for Children and Youth Affairs discussing the Government's stated 'third term' commitment to focus on Early Childhood policy. We also met with Senator Amanda Vanstone, Minister for FaCS and her advisors to consider what we need to do to establish a national secretariat for ASD in Canberra. This has long been a priority of the ACA and it is perhaps our highest priority for the moment. We need ASD to be included separately and independently as one of the peak disability bodies advising the government. The outcome of these discussions has been that ACA in conjunction with A4 is to prepare an application for government funding for this purpose in 2003.

Fingers crossed!

Current Parliamentary Inquiries

There are two key Committee Inquiries happening in the Federal Parliament at the moment that ASD issues need to be brought to the fore. One has just tabled its Report, and one is about to commence receiving submissions.

- 1) The Senate Employment, Workplace Relations and Education Committee has just tabled its report into the education of students with disabilities.

Here is the link:

http://www.aph.gov.au/senate/committee/eet_ctte/ed_students_withdisabilities/report/index.htm

Copies of the report can be downloaded; or if you call the secretariat, they will send you out a paper copy. Key excerpts include:

Diagnosis of autism

4.2 Autism is singled out in this report for particular mention because the full extent of its impact is only now being recognised. Details of diagnosis are given later in this chapter. As the evidence shows, education systems are almost totally unprepared to deal with either its early diagnosis or its treatment. Specialist knowledge and experience in re-programming severe autism sufferers to the point where they benefit from mainstream schooling is very limited.

4.3 Perhaps the saddest representations to come to the committee were those from parents of autistic children. Action for Autism asserted that there was strong evidence that intensive and autism specific early intervention programs designed to treat and rehabilitate children with autism have been shown to be effective and have lasting results. Unfortunately, few Australian children with autism can gain access to effective early intervention. The required intensive treatment is not provided by the health, disability or education sectors. In the mental health sector it is not available to pre-adolescent people. The point was made that:

By the time developmental delays and behavioural challenges in a child with autism reach crisis level it is too late. Intervention for older children with autism is extremely difficult and may be prohibitively expensive. Research shows most Australian children with autism have significant levels of psychopathology (anxiety, depression and psychosis) that often remains undiagnosed and untreated. Children with autism are among the worst affected by mental illness.[1]

4.4 The committee was told that children with autism need early and intensive autism-specific behavioural intervention to prepare them for school. This is needed to teach them the basics of communication: to hear language and to speak. Autistic children need to be taught to learn through imitation of behaviour, which they are otherwise incapable of. In most cases this training is unavailable because there are few autism-specific trained teachers. Most children with this condition have access only to generic programs intended for children with an intellectual disability.[2]

[1] Submission No. 147, Action for Autism, p. 2

[2] *ibid.*

Congratulations to the Autism Behavioural Intervention Coalition, NSW Autism Association, Action for Autism, ACT Autism Association and all the others that put in submissions to this Inquiry. I think it is fair to say that this is to most coverage that autism has had in recent Federal Inquiries. It shows that if we provide the information and put our case in an appropriate and constructive way, we can have an impact.

So now it is your turn:

[Standing Committee on Family and Community Affairs](#)

[Committee activities \(inquiries and reports\)](#)

Inquiry into Improving children's health and well being

Terms of reference

On 17 October 2002 the Minister for Children and Youth Affairs, the Hon Larry Anthony MP, referred the following inquiry to the committee.

The committee is to explore avenues for enhancing parenting capacity and child and family friendly communities in order to overcome current social problems.

The inquiry should cover these areas:

1. How can children's developmental needs best be accommodated in this rapidly changing social and technological environment?
2. What is needed most to strengthen family relationships, parenting skills and confidence?
3. What would a family and child friendly community look like? What practical steps could be taken to strengthen community engagement with families and children?
4. What are the gaps in existing services for children and parents? How could tiers of government and the non-government sector work more effectively to enhance service coverage and delivery?
5. What additional effort is required to meet the needs of Indigenous children, children from diverse cultural backgrounds, children with disabilities, children in jobless families, children known to be 'at risk' and children in foster care?
6. What national goals and targets for improving the health and well being of children and families could be developed to measure progress?

Have your say on this important issue

With this inquiry the committee is seeking new and more effective ways of giving all members of the community the opportunity to make a contribution to the inquiry. Any suggestions for how this might be achieved would be very welcome. To provide these suggestions contact the [committee chair, deputy chair, members](#) of the committee or the [committee secretariat](#) or email the committee at fca.reps@aph.gov.au.

The committee will also accept submissions in the usual way. Contributors making submissions are encouraged to obtain [guidelines on the preparation of a submission](#). These are available from the [committee secretariat](#) or from the committee's website.

In addition, avenues for the committee to meet with the community to discuss issues will be available, including public hearings.

Submissions and other written contributions to the inquiry

Public Hearings and other avenues for discussing the issues

Transcripts of public hearings and other activities

Media releases

Comments to: Committee Secretary on PH: 02 62774566 or FAX: 02 62774844

or e-mail: fca.reps@aph.gov.au

When in Canberra we met with the Chair of this Committee, Kay Hull MP, and although this Inquiry is not specifically about disabilities, she is keen for

members of the autism community to contribute. We may even be able to get a hearing before the Inquiry if the response is sufficient.

Canberra in June

As advised previously, our ASD families 'walk on Canberra' event is set for June 2 & 3, 2003, to be immediately preceded by the ACT Autism 25th Anniversary weekend and seminars. Naturally travelling to Canberra (indeed to anywhere) is extremely difficult for most of our members, but please do think about whether there is a way you or someone in your family can be represented. Perhaps it is worth approaching a local service group to sponsor some families or some cars from your area. This will be your chance to learn about how parliament and advocacy operates in the Australian situation. We promise it will be worth your while, and the more people we can muster, the better the outcome will be.

More details will follow in February, but start planning now.

International Autism News

UK: On 21 November 2002, A Call To Action for Autism signed by 3000 parents of people was presented to Prime Minister Tony Blair on and follow up letters were sent to all Members of the UK Parliament, along with a book on autism. In conjunction with this, a seminar was held and a candlelight vigil took place in outside the Westminster Houses of Parliament.

Some interesting parent advocacy websites in the UK are: www.pace-uk.org (Parents Autism Campaign for Education) and www.hope-tlc.autistics.org Representatives from both these groups attended the World Congress in Melbourne and are keen to share information and further links with A4.

USA: Congressional Hearing Renews Calls For Answers to "Autism Epidemic"

A hearing called by the U.S. Congressional Committee on Government Reform has sparked renewed calls for increased research into the "autism epidemic." The December 10 hearing, which was chaired by Congressman Dan Burton (R-IN), a passionate advocate for the autism community and grandfather of a child with autism, focused on the proposed relationship between vaccines and neurological disorders such as autism. However, the hearing also highlighted that the nation is in the grips of an autism epidemic and that federal government needs to do more to find out why this is.

For more on the hearing and for information on new research into the link between autism and the MMR vaccine, visit the ASA Web site at www.autism-society.org.

That's all for now. I hope that this has filled you in with some of what has been happening with A4 over the past month or so.

May your Christmas be less stressful than you expect it to be, and may 2003 be a positive and productive year for our group.

Judy Brewer Fischer
Convenor A4