A4 Autism Aspergers Advocacy Australia

UPDATE

November 2005
Issue 9

ACA and A4 United on ASD

This festive season people with an Autism Spectrum Disorder, including Asperger's Syndrome, can celebrate a major milestone in national advocacy. For the first time, two national ASD groups, Autism Aspergers Advocacy Australia (A4) and the Autism Council of Australia (ACA), brought their voices together to develop a united submission to federal government.

Hopefully, people will appreciate this is a natural development of our advocacy efforts. A4 was created as a grassroots organisation to focus on national advocacy. Once A4 established a level of initial credibility, A4 and ACA agreed to work together on advocacy and developed our shared Memorandum of Understanding.

Since then, both organisations cooperated closely around the Health Department's Nation Autism Forum. The official report from the forum has been released. More work is required.

All advocacy on ASD issues in Australia is voluntary. Effective advocacy at the federal level is hard work. In relation to health matters, our voluntary effort competes with well-funded professional lobbyists from drug companies, organisations that represent health professionals, state governments, etc. for the attention of politicians and health officials.

Our joint submission results from the voluntary work of A4 members followed by Mick Clark, President of ACA, and Judy Brewer Fischer, who is the A4 representative on the ACA Board. Judy and Mick took a draft from A4 to the ACA Board. The Board provided valuable input. Mick and Judy persisted getting an agreement from the ACA Board and A4. You can download the result from http://www.a4.org.au/documents/ActionsDoHA0511.pdf.

This first-ever joint submission represents a united position suggesting a number of concrete actions open to the federal Department of Health and Ageing.

Success in developing this document is just cause for great celebration. So if you a breaking open a bottle of bubbly, whether it be lemonade, home-made ginger beer or something else, feel free to celebrate this important step for people with ASD in Australia.

Inside this Issue

Disclaimer

Convenor's message

Dear A4 member

I bring you the sad news that our A4 Update Editor, Anita Harvey, has stepped down. For some time she has been carrying a huge workload. Anita is busy with her local activities. The good news is Anita remains an A4 member and may contribute to A4 in other ways.

Many of you have written to say what a great job she has been doing. Let me add a

huge thanks to Anita

for her work editing our as A4 Updates. Her contribution to A4 has been massive. She has helped me enormously. ***Thank you Anita!***

A couple of people have offered to take on editing or helping with the Updates. I will try to hand over to them before the next Update. We can still use "reporters" from each state.

Time flies.

The Health Department and the Secretary released their report from the National Autism Forum (see http://www.a4.org.au/documents/NAF-FinalAug2005.pdf). It is worth downloading and reading this report (at least in my view). Somehow, the main points from the Forum were omitted from the report. This gave us the opportunity to develop instead a list of immediate action items for the Health Department.

We sent you a first draft for comment. A4 got great feedback in return (see **Your say on Health matters** below). Thanks to all those who helped created a shared view with ACA.

A4 should keep the pressure on federal Health to ensure the clinical needs of people with autism are addressed and that health and other outcomes for people with ASD improve significantly.

If we can, A4 should expand our activities into other areas of responsibility in federal government. The Departments that seem to me to be of the most immediate concern are FaCS, Education and Employment. As always, A4 welcomes suggestions and ideas on how these federal departments could improve outcomes or just their services for people with ASD and their families, carers & associates.

We had an initial meeting with the Shadow Minister for Disability, Senator Jan McLucas … who wants further meetings with A4 and with people who are diagnosed with ASD. She said she would ask some Questions on Notice to try to get some information on the record.

Recently, Michael Gourlay, CEO of the Association for Children with a Disability, wrote in his article *Catch Me I'm Falling* in Melbourne Child, about the chronic lack of relevant services for children with autistic behaviour. I am disappointed that he also says ..."most parents accept that they might be part of the problem". I cannot imagine why he says that. I am not a perfect parent but I am not "part of the problem". I try to be part of the solution. My child with autism has some dysfunction; my child who does not have autism has no autistic dysfunction; my parenting does not cause autistic dysfunction, "the problem", in my children. My son's dysfunction is due to his autism, not my parenting. Autism is a clinical disorder and clinical dysfunction requires (and may respond to) clinical services for autism that are outside the normal bounds even of ideal parenting practice. We don't expect parents of children with cancer, or schizophrenia, or heart disease, etc. to regard themselves as "part of the problem". Anyone who suggests I might be "part of the problem" does not represent me or my views.

Regards
Bob Buckley

Supernanny and autism

Supernanny Teams With An Acclaimed Autism Expert To Help A Child Who Is An Outsider In His Own Home On "Supernanny,"

Monday, Nov 14 at 7:30 pm on Channel 9. (AUSTRALIA)

Supernanny Jo Frost teams with world-renowned autism expert Dr. Lynn Koegel to tackle the parenting issues faced by a family whose three-year-old son is an outsider in his own home. This episode of "Supernanny" airs on **Monday, Nov 14 at 7:30 pm on Channel 9.**

Deirdre and Trae Facente don't know how to integrate their autistic son Tristin into their daily life with their twins, Kayla and Marlana (4). Tristin is completely non-verbal, caught up in his own world of spinning, jumping, swinging and, often, taking off his clothes. The only time he spends with his family is sitting at the dinner table. The twins, who demand much of their stay-at-home mom's attention, can't figure out how to play with their little brother. The parents are at a loss as to how to help Tristin come out of his zone and join the family.

Enter Dr. Koegel and Supernanny. Together they refine the classic Supernanny methods and teach all the Facentes Dr. Koegel's inclusion and communication techniques to help engage Tristin. For example, when they introduce the new daily schedule to everyone, Dr. Koegel uses a picture board with Tristin to help him understand in a concrete way.

In just a week, silent Tristin goes from zero words to speaking hundreds of times using over 20 new words. He is bursting with requests to play a favorite game, be tickled or eat a treat. Step-by-step, Jo and Dr. Koegel help the parents keep Tristin from his disruptive behaviors by including him in family chores and activities. These efforts culminate in the boy helping his dad set the table, a seemingly mundane task that is so miraculous for Tristin, it brings tears to Trae's eyes.

Lynn Kern Koegel, Ph.D is one of the world's foremost experts on the treatment of autism. She and her husband, Robert L. Koegel, Ph.D., founded the renowned Koegel Autism Center at the Graduate School of Education at the University of California, Santa Barbara. She co-wrote the bestselling book on autism, Overcoming Autism: Finding the Answers, Strategies, and Hope that can Transform a Child's Life, which was recently released in paperback, and also co-authored, with Robert Koegel, the new book, Pivotal Response Treatments for Autism.

ASD in Federal Government

Recently, A4 was asked which sections of which federal departments are responsible for matters affecting people with autism. We searched various government websites to see what the various departments tell us about their ASD related activities.

Here are some facts that give a context. The Survey of Disability, Ageing and Carers conducted by the Australian Bureau of Statistics (ABS) tells us that in 1998 there were 13,200 and in 2003 there were around 30,000 Australians who report having a diagnosis of autism or a related disorder. The Australian Institute of Health and Welfare (AIHW) reported recently that Autism is the condition most likely to be associated with ‘severe disability’—95.3% of people with these conditions reported severe disability[1].

Disappointingly, none of the government sites mentioned Asperger’s Syndrome.

We searched FaCS for “autis” (so it finds both “autism” and “autistic”. There were very few hits.

The **Australian Government Disability Services Census 2003** tells us 1,187 received support from FaCS. This suggests very few (about 3.9%) people with autism, which is often a

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[1] Australian Institute of Health and Welfare (December 2004) *Disability and its relationship to health conditions and other factors*, Canberra, AIHW Cat. No. DIS 37, p120.

severely disabling disorder, receive disability services. The “census” appears to be mostly about employment services.

FaCS Office of Disability is funding the Autism Council of Australia to do a small research project.

We could not find any link between autism and the following FaCS Branches: "Early Childhood and Communities", "National Disability Operations", "Child Support Policy" or "Child Care Policy and Planning".

Some of the schemes designed to support people with a disability fail to assist people with ASD. The designers of such schemes lack knowledge and experience of effective services for people with ASD; policy developers do not recognise and address the needs of people with ASD. Generic disability services[2] do not meet the specific needs of people with autism, so people with autism miss out on the services they most need.

The Australian National Audit Office recently observed[3]:

> “FaCS could gain a better understanding of demand management issues and quality assurance processes applying to disability services” p15
>
> “the State and Territory disability agencies, and FaCS, have recognised that there: ‘is currently no one conceptual model adopted by jurisdictions that assesses eligibility, support needs and priority for service at both a systemic and individual level’” p16
>
> “Despite a number of avenues for monitoring and reporting performance, there are currently no adequate measures of whether, or to what extent, the CSTDA is meeting its objectives.” p17
>
> “These shortcomings in performance information limit the capacity for FaCS to influence the jurisdictions to improve the efficiency, effectiveness or quality of services the States and Territories are primarily responsible for administering under the CSTDA. These limitations also mean that FaCS’ reporting of the performance of the CSTDA through its Portfolio Budget Statements (PBS) and annual report is not transparent or effective.” p17
>
> “… monitoring of performance under the CSTDA could be improved by the agency gaining a better understanding of demand management issues and quality assurance processes applying to disability services …” p18
>
> The ANOA recommended that FaCS should “develop measures of outcomes, effectiveness, quality and unmet need, and, while recognising the inherent complexities involved, include them in any future CSTDA, or related multilateral agreements”. FaCs agreed. p24

Responsibility for disability related employment services moved recently from FaCS to DEWR. We have major concerns about employment issues for people with autism and their primary carers. As yet, our concerns are not being addressed. There is no sign of any DEWR Branch taking responsibility for the (apparent) chronic under-employment of people with ASD. The only references to "autism" on the DEWR website are in the names of organisations. These relate to contracts with:

- Autism Association of Western Australia (Inc) for Disability Open Employment from15/12/2004 to 24/06/2005 valued at $385,580

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[2] Often called “specialist disability services” by bureaucrats, presumably to confuse themselves, their political masters and journalists.

[3] The Auditor-General, *Administration of the Commonwealth State Territory Disability Agreement: Department of Family and Community Services*, Audit Report No.14 2005–06, Performance Audit, p15.

- Autism Association of Western Australia (Inc) for CBF/AWT Funding from 1/7/2004 to 30/6/2005 valued at $214,231

- Alpha Autism Inc for CBF/AWT Funding from 1/7/2004 to 30/6/2005 valued at $226,401

There seems to be no section in DEST responsible for ASD. The main DEST reference to autism or autistic is to NSW Non-systemic Special Schools being: Illawarra School for Autistic Children; Newcastle School for Children With Autism; South East Sydney School for Children With Autism, Terrigal School for Autistic Children; Vern-Barnett School for Autistic Children (Forrestville); and Wetherill Park School for Autistic Children. There is a reference to one atypical child with autism in an "Evaluation of School-based Arts Education Programmes in Australian Schools". And there is a small grant associated with a national award scheme for a Hervey Bay Special School conducting research entitled "Neurotherapy – An approach to Autism: Neurofeedback treatment and brainwave conditioning is an approach to reducing the negative behaviours that impact on the learning of students with Autism".

The main conclusions are that there are no signs that any section in FaCS, DEST or DEWR recognises that Autism Spectrum Disorders are a distinct disability, and that the ASD diagnosis rate has risen significantly over the last decade. None of these departments has public documents showing services have increased to meet the changing demand resulting from the increased number of people diagnosed with ASD. None of the departments reports on the outcomes for people with ASD resulting from their policies and services.

Government Vision vs child with autism

Have you taken a good look at what the government in your state is trying to do for people with a disability lately? Have you thought about what it means for people with ASD?

Disability ACT has created its Vision and Values Statement. The Vision parts says:

> All people with disabilities achieve what they want to achieve, live how they choose to live, and are valued as full and equal members of the ACT community.

My son is 14 years old and has autism. It is not always easy for me to know how he would choose to live (his family provided intensive therapy just so he could make simple choices in a way we could understand).

As best I can tell, he would choose to live much like most children. He would choose to live in a fruit salad, ice cream, chocolate and pizza factory with a surfing beach out the front door and snowfields out the back door. It would be next door to the zoo on one side and a row of theme parks on the other side.

To my knowledge, Disability ACT has not attempted to determine what my son wants to achieve or how my son would choose to live. Nor do I see any sign that the government plans to help my son reach these objectives.

Some other state governments have delusions like the ACT’s Vision. In Victoria, the Vision and Key Priorities document at http://hnb.dhs.vic.gov.au/commcare/ccdnav.nsf/fid/-FBAF477725C21060CA256EB50002E72C/$file/ECIS_vision_statement.pdf says

> Families caring for a child with a disability or developmental delay are able to access flexible and responsive specialist supports within the universal platform of services, to support them in raising their child within the family and community and enabling them to achieve their developmental, social and emotional potential.

There are lots of weasel words here. "Responsive" means that, unless your needs are trivial, support services are expected/required to say "bugger off" within a few days. "Specialist" means "relating to disability in general and definitely not targeting a particular disability". "Universal" means "one size fits all" ... but may not mean "one size fits all". "Raising their child within the family" means "don't ask for help". "Enabling them to achieve their ... potential" in relation to children with autism clearly preserves the 20 year old expectation that people with autism will be fully dependent through their life; as the "universal platform" model denies access to autism-specific intensive EI that facilitates a whole new potential. I suspect "flexible" means that brochures will bend when pressure is applied. Why not check out your state government and tell us what you think?

So our governments have laudable goals ... that are impossible to achieve; so no one is surprised that when they do not succeed. In this way government avoids discussion of what could reasonably be achieved for people with autism/ASD and why more realistic outcomes are not targeted and achieved.

Our vision for our son is much more modest than the government’s. We recognise that we cannot achieve the impossible, and that we had better face reality and get on with practical goals. Our vision is that

> Our son will have personal and practical education, developmental and life-style goals and will achieve many of those goals; he will have desirable choices in his life and he will realise many of those choices; that he will be appreciated for his stupendous efforts to be part of the community; and that he will experience much joy, happiness and accomplishment in his life, and very little disappointment, abuse or deterioration.

Realising our vision depends primarily on our ability to translate our vision and his goals into reality. While we appreciate any assistance we get from government, we also feel that policies and services that recognise the distinct nature of his autism/ASD could cost the same as (or less than) existing “generic” services and would help our son achieve more of his education, developmental and life-style goals. We recognise that service providers have particular jobs to do. And that means we are the only people who are focussed specifically on achieving our son’s goals and preferred outcomes. Achieving our vision for our son is all up to us.

Bob Buckley

From Federal Parliament

The Senate Notice Paper, under Questions on Notice, shows ...

Notice given 12 September 2005

1172 **Senator Allison**: To ask the Minister representing the Minister for Health and Ageing—With reference to the answer to question on notice no. 2018 (Senate Hansard, 10 February 2005, p. 19747), indicating that the Commonwealth Scientific and Industrial Research Organisation (CSIRO) no longer undertakes research in the area of diagnostic ultrasound, and that the National Measurement Laboratory was deferring ‘further investigation of the needs of this field pending the establishment of the new National Measurement Institute in July 2004’:

...

(8) Given the epidemiological and laboratory evidence from around the world that indicates ultrasound treatment can result in learning difficulties, a significant rise in left-handedness in boys, auditory problems, **autism**, growth retardation, dyslexia and delayed speech development, will the medical profession in Australia be advised to warn women of the possible negative bio-effects before ultrasound treatment.

Your say on Health matters

Hi Bob,

Just one little note. I would like to the Australian Government take a stand on co-ordinating a minimal education program for Children with Autism across Australia. For us living here in Darwin, we do not appear to receive the same professional intervention and education training as compared to southern States…

Keeping in mind I believe Australia is behind other places such as US, Greece and the UK.

Is it not that we are all Australians and all of our kids are entitled to the same education irrespective of where we live????

I have tried to speak to a federal Minister here, but he passed it off to the territory Government, but it's like hitting you head against a brick wall with the Territory Government… So as I'm understand Tasmania, Victoria and I believe Queensland have recently reviewed the services provided in these states for ASD, why can't the Federal Government tap into this information and provide a standard….

I see this might turn into a big issue, as other organisation representing other persons with disabilities may request the same, so the Federal Government would be forced if they do it for one… So I presume the response would be to pass it back to the states… However, I would like the Federal Government, to acknowledge the increase the number of persons diagnosed with Autism and the possible cost affiliated with looking after these persons in the future if they do not receive appropriate education… Meaning the federal Government needs to force the states to do something, or it will cost the federal Government more in the future… The is something that most MP's don't care about, it's usually something you need to put to Treasury – they are usually the ones concerned about monies in the future…

Alright so my proposal would be that the Federal Government finance a consultant, to review services provided in each state and then services provided/recommended in the US and UK… then to derive a minimal education and early intervention *pro forma* for each state/territory to abide by….

Okay I'm not right into politics, so I'm not sure if that's as straightforward as I've pointed out.

Thank you in advance for your time reading this email.

Cheers
Joseph

Hello Bob,

Thank you for starting the discussion rolling. I will be tabling your draft with the Autism Victoria State Council in a couple of weeks along with the document sent out by Pyne's office earlier this week. I will also push the ACA Board to be proactively involved in moving dialogue with the respective advisors etc in Canberra.

Kind regards,
Amanda.

Especially agree that the medical expense tax rebate should increase.

As it is we are better off claiming that the therapists coming in are in-home care childcare workers and getting a 30% rebate on out of pocket expenses than the 20% medical expenses rebate.

Should at least be on parity with childcare rebate!!

Stephen

Dear Bob

You do a remarkable job and seem to be making real differences. I don't have time to read many emails but always read these.
Regards Jo

Bob,

I would add to the list the issue of medications and the PBS, I can provide further info on what meds etc if you want.

I would also suggest training child health nurses in early detection of ASD. As far as professionals go we are very good at looking holistically at persons and child health nurses will often pick this up.

Jude

Bob, I really like this; given the limits at present I think this is a great start and addresses some of the major obstacles.

Infrastructure and appropriate schools is a huge problem but I think that's further down the track? Jenny

Bob,

Allison and I had a look at the options and picked the following.

- A home for ASD in health
- National ASD register (important to know numbers)
- AIHW report (please note I found a report Via the mercury from the AIHW that said that autism was the most severest disability the report was done by Dr Wen)
- Centres of Excellence for ASD research and teaching
- Health professional awareness
- Medical Expenses rebate

Peter & Allision

Hi Bob,

While all are worthy aims, I think that having a national register of ASD sufferers is crucial, especially for lobbying for resources.

Currently I imagine it must be very difficult to get ASD "on the radar" of governments without knowing the numbers involved. The sad reality is we have to compete for resources and it's made all the more difficult without the hard facts.

Cheers,
Simon

Dear Bob,

Thanks for this update. As you advise, I am not holding my breath, but...

I would suggest that the list presented to Mr Pyne MP covers the first five points in your discussion paper, with ***possibly*** a sixth point that requests financial assistance for families to meet the medical costs of ASD.

The first five points deal with recognition of the problem, quantification and longer term research based solutions. If we can get the Federal Government to buy in to the fact that there ***is*** a problem then this would be a momentous step. But until we secure their recognition of the problem, I think it would be very unlikely that we could win on the point of securing financial assistance for families through Medicare or Private Health Insurance.

Another suggestions, although it would require both some funds and ***recognition*** by the Federal Government:

- Some kind of grant (and/ or expertise) to allow ACA to promote a National Autism Day each year, with the aims:

1) to achieve a national day that is as recognisable to the general public just as easily as Jeans-for-Jeans Day or Daffodil Day, etc. National Autism Week seems to be gaining momentum each year, which is wonderful, but I still feel that we have no-where near the recognition in the community as other serious health issues. If you ask the average person from any Australian city if they recall this year's Daffodil Day they will probably say "yes", but it would be a difficult task to find anyone who could recall this year's National Autism Week.

2) to raise funds for Research Centres of Excellence.

I hope all goes well in deciding on the list of issues to present.

Best regards,
Ken

Hi Bob

I'm very curious Bob. How is your information regarding Early Intervention Funding? How are these funds allocated per child? What is the money spent on? I'm from Regional Victoria so services are limited.

Appreciate any info. I'm just fishing!
Jenny

Dear Bob

Just managed to read the document you sent around for review re: Items to put forward to federal advisor for ?health minister.

Must agree on all counts!

Well done!

Cheers
Rox

Bob,

As the ASSN webmaster, I have added this on the ASSN site at www.assn.org.au/calendar.htm

Bob

My comments are;

Interesting read.

As a parent of an 8yr old with Asperger Syndrome, my personal priorities would be no. 5. Health Professional awareness (where they may have heard of Syndrome, info is often very outdated or boy relevant), I also thought no. 7 should be a higher priority, as we don't use our health cover for this at all, due to the costs of increasing from basic to a higher level.

I thought a specific area within Health was a GREAT idea to push, an area to go to be a coordinator/ information holder on where to go to get help, services available etc.

We also experience many (what I term) cross border issues. Living in Qbyn, working and paying tax in ACT and schooling in ACT, locked out of ACT system i.e. ACT Therapy, not having services in NSW, Queanbeyan, travelling to Sydney for specialists etc.

In the Asperger Syndrome Support Network meetings, the most common parent compliant I hear is "that they are told by health system that their child is not BAD enough to warrant any help through the system and they have to find help privately, at often their own cost, and where, who does anyone else use."

I hope I have been on the right track here for you.

Many thanks Bob, you are a gem and deserve much thanks for all the hard pushing you do on our behalf.

Juanita

Book Review

Denise Crouch (2002), *Patience, Love and Autism*, Metro Press, Perth.

In her booklet (170 pages), Denise Crouch recounts her experience as a teacher assistant supporting children on the autism spectrum. She describes the support she provided in mainstream primary and secondary education settings for students whose ASD (in some cases Asperger's) affects them to varying degrees. Her perspective is one that is rarely documented.

Denise writes about her first encounters with students, and her efforts to support her students and longer term results. She shows openly how her initial attempts to communicate with her students were not always an immediate success, and how she went about changing her approach to improve outcomes. She describes how she varied her methods until her students achieved each of their learning goals.

Denise uses simple and easy-to-read language. Her descriptions are succinct. Her passion and commitment are evident.

An experienced teacher assistant said …

> High school frustrations are difficult for every child but especially for one with a disability. Although the initial movement and change from primary school to high school is tough, having someone there who you know and have a rapport with makes that change so much easier. Denise showed how keeping both Ben and Jason in a separate class for the first semester and then slowly integrating them into different subjects made it easier for the boys to cope with their new situation. With every challenge that was given to her by the boys she stood firm on them being in the mainstream classroom and persisted with the support of the their teachers to keep

> them there. The two boys were eventually integrated into all areas of the school including woodwork and metalwork classes where potentially dangerous tools were used.

This booklet might help others who are thinking about taking a role supporting students with ASD, or who already have a role supporting a student with an ASD and want some inspiration. It could help a teacher who has a student with ASD and in guiding an aide.

Patience, Love and Autism is available for $15 and $3.20 postage for 1 book ($7.20 for 2—4 books) from Denise Crouch, PO Box 320, Kelmscott WA 6991 (atlantis@indigo.net.au).

Letters / Emails

> Please send letters to edit@a4.org.au. Letters sent to the editor may be published unless they are clearly marked “not for publication”. Normally, they will appear with your full name and state unless you mark them clearly “anonymous” or “first name only”.

Bob

I did some Web search on child guard and tracking devices. As far as Childguard is concerned there is only the one that you have already found with a max of 20 feet. But I found another website: http://www.wherifywireless.com/ which has a promising device that won the new inventions awards. They are planning on launching it in Dec or Jan and the cost is between $150 to $300 plus telco costs of approx 50 cents per day. I have spoken to Ricky Norman (Chairman) in WA. He says that it is suitable for a child with special needs, who is non-verba. The way it works is by parents tracking it on the internet or a mobile phone with WAP capability. Edwin might be interested in this too. Ricky is happy to talk to you if you want to know more. His numbers are: 08-9347 4444 or mbl 0409 114547. You may also want to look at the smh article http://www.wherifywireless.com/news/pressrelease/2005.10.18.pdf .

regards Caroline

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 help and constructive criticism.

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