A4 Autism Aspergers Advocacy Australia

Hello again A4 members,

Drum roll please…………… Announcing that the new A4 website is to be unveiled and opened for business next Monday 2nd June 2003! A4 is organising a special online event to mark this day, so reserve a spot at your computer at 8 pm on Monday night, and make sure that you read your emails this week to ensure that you have the necessary information to log in and be part of our A4 online chat. Further details and the all important new website address will be forwarded to you in a separate email. Can I take this opportunity to thank Bob, Cris, Larry, Jo, Denise and all who have contributed towards getting our site up and running. Our website will be a continually evolving project and we look forward to your feedback, your suggestions and your content in the future.

The launch of the new website will also mark some new changes in the way A4 operates. Firstly, due mainly to some extra family commitments, I am handing over the A4 Convenors role to Bob Buckley. As you all know, combining ASD advocacy and family life can be challenging and I think it is important for people to move through different positions in an organisation and to have time out occasionally to ensure that the creativity and enthusiasm is maintained. I suspect that many of you would know Bob already through his involvement in A4, in Action for Autism and the Autism Council of Australia. His knowledge and experience with advocacy is quite incredible and I have relied on him very heavily over the past few months, so the transition should be a very smooth one.

But you won’t be getting rid of me this easily. I will be staying closely involved and remaining on the steering committee, as well as taking on some new autism related projects.

Also, please note that the aaadvocacy@bigpond.com address will cease when the website is operational and contact with A4 will be primarily website based.

So, thank you for all your support to date and I am sure that Bob will appreciate any offers of assistance and any new keen recruits to the various committees being formed. If you have any spare time, a positive approach, and a passion for furthering the understanding of ASD with those that matter, please do not hesitate to get further involved.

There is much to be done!

AUTISM WEEK: 11 – 18 MAY

From all reports there were some terrific events staged across the country during Autism Week, as highlighted in our last update. However our A4 friends in Tasmania missed out getting their week of activities included, so here is a brief summary:

> The 4 autism groups in the State - Autism Tasmania, Giant Steps, Autism Behavioural Intervention Tasmania & Dept of Education's Autism Network of Tasmania – all worked together to develop the week's program.
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> We had community ads on WIN & Southern Cross TV, integrated with a poster campaign, several media items, almost 20 community displays around the State, a statewide charitable collection day on Friday 16 May and 3 days of superb, theatrical face-painting of prominent Tasmanians in public locations in Devonport, Launceston & Hobart on 12, 13 & 14 May - under the banner of "Face Autism".

Well done Tassie, and best of luck for your Inaugural State Conference to be held in Hobart next month on June 20 & 21.

AUTISM IN PARLIAMENT

One of the things we have been working on is getting autism spectrum disorder into Hansard and into the minds of our Federal Parliamentarians. Senator Sue Knowles has been a supporter of A4 since hearing about our formation after the Melbourne World Congress.

We sincerely thank Senator Sue for raising Autism awareness as a Matter of Public Importance in the Senate during Autism Week.

"SENATE - 14 May 2003

Senator KNOWLES (Western Australia) (12.45 p.m.) —I rise today in the Senate to make some comments on autism. This week is National Autism Awareness Week, and I think it would serve us all well if we were more aware of the trauma associated with autism. Thanks to the Developmental Disability Council of Western Australia, I have been honoured and privileged to have been adopted by a family that has been affected by autism. The family who decided to adopt me under the Adopt-a-Pollie program are the most wonderful people you could imagine and they are suffering under immense strain. I will give the Senate a brief outline of family.

It comprises a single mother who has four children under the age of 10, three of whom are autistic, two of whom are non-verbal. That mother is nothing short of amazing; she is remarkable. She is studying full time at university to do special ed, and she also has an illness herself. She copes remarkably well but would cope a whole lot better if she had more support. That is not to belittle the people who support her in everything she has done thus far, but it is a very traumatic situation for any family to discover that they have an autistic child, let alone to have three autistic children in such circumstances.

What is autism? Autism is a puzzling disorder that affects one in 1,000 people. Scientists are still trying to discover why it happens. A child can look perfectly normal when it is born and its behaviour can be essentially perfectly normal in its early and formative years. Autism may well not be diagnosed until the child is about three to five years of age, when it becomes apparent that some of its behaviour is different. Autism can range from mild to severe, and it therefore affects children very differently. It affects one person differently from another. In this one family alone, there are three autistic children, and two of them are non-verbal. Boys are more likely to be affected than girls. It needs to be emphasised that poor parenting is not a cause of some of the behavioural problems that are associated with autism. The disorder causes problems with social interaction and behaviour. It is sometimes—but certainly not always—associated with an intellectual disability. In fact, it can be quite the reverse: some autistic people can be absolutely brilliant at certain things. It is their focus on certain issues that, at times, makes them brilliant on a particular subject.

Annually about 900 children are diagnosed with autism. Autism significantly affects a person's ability to communicate and interact socially, which in turn, of course, affects their behaviour. When one has difficulty getting across to another what they want as a child—and even as a young adult—then that will create frustration and it will create further tension in that environment. As far as communication is concerned, emotions and words can be very difficult to comprehend. It is very difficult, in many ways, for children with autism to link words with their meanings. That is where the mother of the family with whom I have contact is a very sensible parent. She keeps on saying: `I don't necessarily want my child to come home from school with a lovely little card that they have made. If my child came home and I knew that he could identify an arm, a hand, a leg, his face, his eyes, his ears—that would be teaching him something in his life skills.'

I think that is a very important point that we need to be able to get across to the educators, who I believe do a very good job. The role of a special education teacher is not an easy one and it is one that we should never, ever take for granted. But the mother's words were highlighted, only a few weeks ago, when the youngest child of this family, who is only about three years of age, started to display an unusual tendency to topple over. It was very difficult because the mother did not quite know what was wrong, and the child could not tell her what was wrong. Invariably, those children do not feel pain and, therefore, the possibilities were endless.

In the end, the mother took the child to a doctor who referred the child to the medical emergency centre in one of the hospitals in Perth. Because this child—the most absolutely delightful looking child—looked perfectly normal, everybody started talking to the child: `Come on here, mate, do this, do that, do something else. Does this hurt, does that hurt?' The mother kept saying: `He is non-verbal. He does not speak. I don't know what's wrong with him.' The whole process undertaken by the doctors and nurses, and the mother and father—because the father came in to lend assistance, and he was there trying to hold the child down while they were doing tests—became very difficult. To cut a long story short, the little boy was eventually diagnosed with a broken kneecap.

We do not understand, as people who have been blessed with all our faculties, because we can say, `My arm hurts,' or, `My knee hurts.' We go to a doctor and it is done. But this is a very special group of people. There are significant difficulties with some of the verbal sufferers, but particularly with the non-verbal communicators. As a result, the child will grab what they want or lead one to what they want. They may, in fact, parrot words that do not necessarily mean what they want them to mean at the time. Their senses can be confused; a sudden noise can be terrifying to them; silence can be very loud to them. We need to create awareness, particularly during Autism Awareness Week, of what we as a community should be doing.

There is enormous stress on the families of sufferers. There is enormous stress just in doing something as simple as going shopping. I cite this particular family again. The mother goes to the supermarket with the four children—there is no-one else there at the time to look after the children—and her gorgeous eldest son puts the little tot in a trolley. He wheels the little one around in one trolley, and mum has the other two children beside her while she wheels another trolley with the food in it. In many respects, the eldest one is almost being forced to be older than he really is, because, even though he is autistic himself, he is not non-verbal. He gets tired as he is pushing the trolley with his little brother in it. When they get to the checkout, the mother is confronted with the checkout line, four children and a trolley full of groceries. I think being at the end of the checkout line is pretty frustrating just on my own, let alone if you have four children and a trolley full of shopping. Then, when she gets through the checkout, she has had to park a million miles away and has to get the trolley and her four children to the car.

We have ensured that this family has an ACROD sticker so they can park at the door of the supermarket, but that process was not necessarily easy, because the actual recipient of the ACROD sticker is not theoretically disabled. As a community we need to make life easier for the sufferers, and also for the parents of these children. Difficulties are created during the day-to-day trials of running a household at night, where you are trying to cook a meal and bath the children at the same time, and where there is a propensity for one child to put a hand in the oven or on a hot pot on the stove or whatever while the others are getting in and out of the bath. A lot of people do not understand the physical demands, the frustration and the community isolation. They look at these particular children and say, `They're just badly behaved. They're just rotten little kids.' They all look gorgeous: they are dressed beautifully, presented beautifully and everything else, but they have behavioural problems from time to time. In turn, that puts pressure on the family unit that can lead to separation or divorce. Therefore, the chance of burnout of the main carer is potentially very real.

The question of what should be done about this problem is one we, as a parliament, need to look at. I know our policy is very firmly devoted to ensuring that there is overall mainstream disability funding. Of course, there are also state based responsibilities: the states have a responsibility for early intervention, school age support services, family respite services, residential services, employment services and family support. That is all very well, but does it work? When I was confronted with the problem of this early evening rat-race, I said to the mother, `Are there people who could come in and help you at the peak times?' She said, `Only if I decide that my need is greater than somebody else's.' That in itself is difficult. To then try and get volunteer support is somewhat challenging; nonetheless it can sometimes be achieved. But we then have to make sure that the volunteers do not get burnt out.

In this important week of autism awareness, I think it is very important that we, as a community and as a parliament, try and focus on what can be done to help the sufferers and also the carers. I know we have made carer payments available for people in circumstances such as this, but sometimes money is not the only solution; actual hands on deck can help resolve a crisis and take away some of the load. In the family I spoke of, both parents love their children dearly—there is absolutely no question that either one of them is abrogating their responsibility to these children. I think that is the case wherever such a disability occurs. We need to try and focus on those questions: how we can help them through their education and how their education can be geared towards their life skills as opposed to doing nice little things that might make them feel good at the time. We need to train them and guide them towards areas that will give them a future somewhat independent of their primary carer."

NATIONAL ACTION PLAN FOR AUTISM

The A4 Committee has been working on a document that we can use in our representations to Federal Members of Parliament and decision makers, to succinctly outline our cause.

This needs to be no more than an A4 page, and the issues must be those under the jurisdiction of the Federal Parliament.

Following this is a **draft** document for your comment and input. Please read it carefully and let us know what you think.

Two things to note: The document needs to be easy to read, preferably to fit on one page. Also it must be nationally focussed with the issues highlighted being under the jurisdiction of the Federal Government.

A4 National Plan of Action
Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is a distinct disorder that:

- Impairs a person's communication, social function and behaviour;
- Requires specific clinical attention;
- Is neurological in origin; and
- Is a lifelong condition.

The rate of ASD diagnosis has increased.

Autism was regarded as a relatively rare disorder but diagnosis rates for ASD are rising alarmingly. Now Australians are diagnosed with ASD at a rate between 6 and 10 children per 1,000 births. The rise may be due to increased awareness resulting in better recognition of symptoms or rising numbers of people with autism. Both factors may play a part.

Appropriate attention to and policy for people with ASD, including some of our most vulnerable citizens, would greatly improve their health, education, independent living and employment outcomes. Service and resource provisions are not increasing to meet the needs of exploding numbers of people with ASD. As a result, outcomes for some Australians with ASD are amongst the worst in the nation.

What are the problems?

- People with ASD have distinct needs yet ASD is mainly treated inappropriately as a type of intellectual disability.
- Any relevant services are fragmented and rarely combine effectively to meet needs.
- Limited service availability denies people with ASD timely access to essential services.
- Clinical, teaching and support staff lack adequate ASD-specific knowledge and expertise.
- Services do not meet the needs of families particularly in relation to information, treatment, education, respite, recreation and family support

What is needed?

- Recognition of ASD as a distinct disability, preferably through legislation
- Access to diagnosis, comprehensive assessment, and effective early intervention without waiting periods
- Education supports based on individually designed programs under specialist professional supervision
- Appropriate investment in research, training, knowledge and expertise
- Service redesign for person-centred integration of supports and easy access to information
- Investment in skill development for parents and carers, and enhanced family supports
- Employment and training supports for people with ASD

What can the Commonwealth do now?

- Provide ASD-specific places in early intervention, early childhood and pre-school services
- Create a Commonwealth ASD Taskforce involving Departments of Health, Education, and Family and Community Services
- Recognise ASD as a distinct disability through distinct planning and monitoring (separate budget and report lines from intellectual disability and/or general developmental delay)
- Report outcomes for people with a disability rather than counting the service provided
- Contribute to ASD diagnosis and treatment though Medicare and private health insurers
- Encourage ASD-related research and professional development

INTERNATIONAL NEWS

To get you thinking about our national action plan, please check out these documents from the UK & the US, they are sure to get you thinking!

A new report has been published by The National Autistic Society to mark Autism Awareness Week 2003. **Autism: Rights in Reality, How people with autism spectrum disorders and their families are still missing out on their rights,** claims that people with autism are still falling between the gaps when it comes to getting the support and benefits they are entitled to. The report shows that people with autism and Asperger syndrome do not fit current ways of thinking about disability nor the eligibility used to measure support needs of people with disabilities and their families.
The report is available in PDF at Report Summary Rights in Reality[1].

UK Manifesto

On Wednesday 14 May 2003, the All Party Parliamentary Group on Autism[2] (APPGA) launched its Manifesto for Autism. The Manifesto sets out four general principles and eleven specific objectives to deliver better services and support for people with autism, to be achieved in the next ten years. It stems from extensive consultation across the autism movement, with contributions to the Manifesto coming from people with autism, parents and carers, local groups and national organisations. In order to raise awareness of the Manifesto the Officers of the APPGA have tabled an Early Day Motion (EDM), which MPs can sign in order to express their support for the Manifesto. Early Day Motions exist to allow Members of Parliament to put on record their opinion on a subject and canvass support for it from fellow Members.

To see the Early Day Motion highlighting the Manifesto go to
edm.ais.co.uk/weblink/html/motion.html/ref=1164

To download Manifesto
http://www.nas.org.uk/policy/parl/appga/docs/manifesto.pdf

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[1] http://www.nas.org.uk/mediacen/aaw03/aaw03_ew_execsumm.pdf
[2] http://www.nas.org.uk/policy/parl/appga/index.html

AUTISM SUPPORT FROM USA PARLIAMENTARIANS AS WELL ADVOCACY IN WASHINGTON

Coalition for Autism Research and Education
2003

Information and Updates

Dear Friends,

As you are aware, during the last session of Congress, Representative Chris Smith and I founded and co-chaired the first-ever Congressional Membership Organization dedicated to autism advocacy on Capitol Hill—The Coalition for Autism Research and Education (CARE). Over 180 Members of Congress from over 40 joined this bipartisan and bicameral effort.

We still have much work to do, and thus both Rep. Smith and I are once again proud to serve as co-chairs for the Coalition for Autism Research and Education for the 108th Congress. As we continue to build support from both the House and Senate, I will update this list as new Members are added. If your Representative is not yet a Member, I encourage you to contact them directly and share your views on the importance of autism advocacy.

The goals of the bipartisan Coalition for Autism Research and Education will include, but are not limited to:

- Increasing general awareness of autism and autism spectrum disorders among Members of Congress and policy analysts in federal government;
- Educate Members of Congress on current and future research initiatives regarding autism;
- Serve as a forum where autism-related policy issues can be exchanged, debated, and discussed;
- Bring together public, private, and government entities to pursue legislative initiatives that will help facilitate advanced treatments—and ultimately a cure—for autism spectrum disorders.
- Promote all means to ease the burdens of families and loved ones affected by autism

Please keep in mind that these are general goals for CARE. We are open to suggestions from the families, friends, and loved ones on the front lines of the war on autism. I want to personally thank each and every one of the parents and families who have dedicated themselves not only to their loved ones affected with autism, but also to raising awareness of the need for federal attention to this devastating and life-long disorder.

Sincerely, Mike Doyle
Member of Congress

& an interesting new report from California,

California Autism Cases Nearly Double In 4 Years

A new report released this week by the California Department of Developmental Services shows that new cases of diagnosed full syndrome autism in the state doubled in the four-year period between 1999 and 2002, and increased a staggering 634 percent in the 15-year period from 1987 through 2002. The new California report documents a significantly greater growth rate than the 273 percent increase previously reported by the state for the period 1987 to 1998.

This dramatic increase is all the more astounding in that both studies deal with only full syndrome autism and do not account for the rest of the disorders in the autism spectrum, such as Asperger's Disorder or Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). It is important to note that the diagnosis of full syndrome autism historically occurs at a much smaller rate than many other categories on the autism spectrum.

"This study confirms ASA's stated position that the growth of autism in children is accelerating. It is more imperative now than ever before that we step up our efforts in getting children diagnosed and treated as early as possible," ASA President Lee Grossman said.

To view a copy of the report, click here or go to the California Department of Developmental Services Web site - www.dds.ca.gov/autism.

A4 PROMOTIONS

The news here is not so good. Unfortunately our first appeal in March to A4 members to purchase our own custom made A4 promotional items and help raise some much needed funds, resulted in 1 firm order. Our renewed appeal last month raised the commitments to 6 orders, and we need to sell about 80 of each item in order to break even. Looks like we will have to wait a little longer before we start to wear our support of A4 on our sleeves..........that is unless there is a flood of orders in the next week or two.

So, please, if the order form is still sitting in your in tray awaiting attention, do not delay any longer.

Send it to: A4 Promotions, P.O. Box 762, Hawthorn VIC 3122
or contact Cathy at lwryan@bigpond.net.au

Talk to you all on Monday, on line!

Kindest regards
Judy Brewer Fischer