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Self Advocacy

Members of the Australian Autistic Community who have long been involved in Self Advocacy are pleased to announce formation of ASAN AU (AUSTRALIA).

ASAN AU is an affiliate chapter of ASAN www.autisticadvocacy.org

About ASAN in America

The Autistic Self-Advocacy Network (ASAN) is a non-profit organization run by Autistics (those on the Autism Spectrum), those with other unique neurological types and neurotypical family members, professionals, educators and friends. ASAN was created to provide support and services to individuals on the autism spectrum while working to change public perception and combat misinformation by educating communities about persons on the Autism Spectrum.

About ASAN AU.

ASAN AU is run by Australian Autistic adults who have been involved with self- advocacy for a number of years and invites membership from autistic and Asperger youth and adults who wish to receive support to engage in self-advocacy.

ASAN AU understands the following:

- Autistic citizens are capable of contributing to society and enriching the lives of their families and communities.
- While Australian society provides supports and accommodations for many of its citizens, there is little understanding of the specific needs of autistic children and adults.
- Autistic adults want be involved in the planning of services to be used by themselves and their peers. Inclusive and equitable services can only be developed when

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stakeholders contribute positively towards promoting their own wellbeing and connectedness to society.

- Autistic adults want recognition of the fact that autism is a life long condition that impacts both positively and negatively upon a person's ability to function in society.
- Autistic adults recognise that a proactive stance means that the thousands of children in early intervention and education programs now will hopefully inherit a more effective system and a more understanding community.
- Autistic adults are in need of support in the following areas:

Communication	Sexuality	Cultural identity
Accommodation	Crisis Management	Healthcare
Education	Criminal Justice	Advocacy
Employment	Socialisation	

The extent to which autistic adults are and have been ignored saddens ASAN AU members. All Autistic citizens are capable of contributing to society and enriching the lives of their families and communities, but need the support and acceptance of society as a whole. An investment in the future of people with Autism is an investment in the skills and talents that are untapped by virtue of this group being a silent demographic.

Convenor's message

Dear A4 member,

This has been a tragic month. The lack of adequate support for people with autism was fatal for two teenage boys with autism and for a carer (see below). Some may ask will the governments recognise their systemic problems; will these deaths affect government decisions? Only if we can hold them accountable.

In coming months, I will suggest ways to do that. A4 is interested in your ideas and suggestions too.

No doubt you have seen the media frenzy over the annual carer payments.¹ The campaign resulted in the Government paying the one-off bonus for at least another year. This shows well-run grassroots campaigns are effective.

You may be wondering why A4 was not active over the carer payment. My view is that the carer payment is not an ASD-specific issue. I see A4's role as focussing on ASD-specific matters and primarily about people with ASD rather than their carers. There are other groups that focus on carer issues ... and A4 would support their efforts when appropriate and needed. The carer groups did not need our help in this case. I hope A4 members will support other organisations relevant to them.

The **1000 hours** campaign got off to an excellent start (see www.1000hours.com.au). There were around 2,000 registrations in the first 48 hours. There are around 6,000 registrations as I write ... but it is slowing down.

Thank you to all our A4 members who have registered with the **1000 hours** campaign. Thank you for passing it on to others.

Also, a very big **THANK YOU** to all the people who wrote back with their comments. I am (and A4 is) very aware that the Government's version of early intervention does not address the needs of most of our members, whose children are older ... or were and will be diagnosed

¹Too many articles to mention them all. Try these first ...

<http://news.smh.com.au/oneoff-bonus-may-remain-rudd/20080311-1yks.html>

<http://www.news.com.au/dailytelegraph/story/0,22049,23359815-5006009,00.html>

<http://www.abc.net.au/news/stories/2008/03/09/2184251.htm>

later in their lives. It really does help to have you, our members, tell us what you want and reinforce what A4 is doing.

Some of the comments I received are included in a separate article (see below). A4 will use these comments to try to convince our Governments that they still have a lot to do to address the needs of people with ASD. Please keep sending your comments to us.

The 1000 campaign added a comments section to its registration process when I mentioned the comments I am getting back after sending out the 1000 hours email to our members. I am keen to see what comments people put there as well.

The nation has ongoing issues with services for children and young adults with severe disability (often autism/ASD). For example, some of the people who are most severely affected are placed inappropriately in aged care facilities (see *Disabled to be offered alternative to nursing home care* <http://www.theage.com.au/news/national/disabled-to-be-offered-alternative-to-nursing-home-care/2008/03/15/1205472164082.html?page=fullpage> and <http://www.ypinh.org.au/>) ... because Governments closed all the (slightly) more appropriate services. This issue has been on the agenda for years. The lack of real progress shows Governments lack commitment to people with a disability.

Governments typically prefer generic disability services that do not provide appropriate services and support rather than address the rapidly growing demand for substantial autism-specific services.

The AABASD has released its latest communiqué (see the article below). The communiqué announces the partnership between A4 and AABASD trying to initiate a “parliamentary breakfast” during *Autism Awareness Month*. This collaboration is a sign of the emerging unity in Australia’s ASD organisations. Such unity will help progress discussions with government over services to meet the needs of people with ASD.

In recent weeks I have seen two powerful films on autism.

I saw *The Black Balloon*. I felt the representation of autism and its effect on a family entirely credible. The acting, directing and writing is remarkable.

While the film was set 30 years ago, it seemed quite similar to how things are today. It is disappointing that here in Australia we have made so little progress in that time. Some of the key issues depicted are:

- The lack of appropriate services and support
- Bullying of people with a disability and their siblings
- Poor awareness, tolerance and support from the community
- Utter dependence on caring mothers, and the burden severe (and untreated) ASD imposes on the whole family

This film may leave young men wishing for a brother with autism so they can attract the sympathy of an incredible girlfriend.

On ABC2 I saw the short documentary film “Make me Normal” (see <http://www.filmakers.com/indivs/MakeMeNormal.htm>). This film is about several young people with ASD who are quite articulate but still struggle with their ASD. The students in the film are very different from each other. The film shows how these particular students have significant self-awareness, quite good social skills but still struggle with functioning effectively in our world.

Responses to this film vary. It presents just a few students on the spectrum. It shows their response to their “condition”. It shows the approach used in a specific school.

NAS response to this film (from around 2005) can be found at <http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=459&a=7044>. Other information includes:

- Interview with Zac Beattie, producer of the 'Make me normal' documentary at <http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=253&a=7099>
- Interview with Jude Ragan, head teacher at Spa School at <http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=591&a=7101>
- http://en.wikipedia.org/wiki/Spa_school

I am unaware of anything quite like the Spa School in Australia catering for students like these. I would like to know the long-term outcome for this approach. I doubt the approach(es) shown in the film would suit all students.

One of the more interesting recent international stories comes from developments over young Hannah Poling and issues raised in the US Vaccine Court.² However you interpret this story, it does establish a clear link between vaccines given to young children and symptoms of autism in at least one case. From now on, anyone saying “there is no link between (the symptoms of) autism³ and vaccines” is either ignorant or lying. In either case, they are unlikely to provide good advice.

This type of autism does not come as a surprise. Like many others, I have been expecting for a decade that this type of autism would be discovered.

Nor does this finding/result(?) prove that vaccines are to blame for the huge rise in autism diagnoses. That issue remains the subject of ongoing debate and research.

Expect that the type of “autism” Hannah Poling has will be defined out of the ASD category just as Fragile-X is now seen as “not-autism” ... though changing the name of her condition will not address her symptoms. This case will be seen by some as a matter of misdiagnosis ... but I doubt those people will advocate that everyone with a diagnosis of ASD be screened for this new disorder, and unless they do we cannot take their view too seriously. At this stage, we do not know how much of the evidence base for autism treatment this affects. Until we properly understand what is different between this new condition and autism, we should continue to treat this new condition the same as we treat a person’s autism/ASD.

This case may have more scientific than legal significance. A better understanding of the biological and genetic basis for the symptoms and the underlying condition usually leads to better outcomes for people with the same type of condition ... eventually. That is a good result.

We do not know how many people with ASD have a similar etiology to Hannah Poling. There are suggestions in the media that her condition could affect just 1 in 4,000 or the population. But the DSM-IV still says autism affects 4 per 10,000. On the basis of these two (highly questionable) prevalence rates, this “cause for autistic symptoms” could (though on the basis of other evidence, it is not likely) account for around half the expected autism diagnosis in the community. But it does not (yet) appear to account for half the cases before the US Vaccine Court or we would expect to have heard more about it by now.

Like many developments, this raises more questions than it answers.

Regards
Bob Buckley
22/3/2008

² see <http://onedadsopinion.blogspot.com/2008/03/autism-mito-vaccine-court-and-polings.html>, <http://www.salon.com/news/feature/2008/03/13/poling/>, <http://www.msnbc.msn.com/id/23519029/>, <http://www.time.com/time/health/article/0,8599,1721109,00.html>, ... google as many links as you want.

³ Since autism is defined by its symptoms, autism and “symptoms of autism” are the same.

The Black Balloon



If you can get past the clichés you will be rewarded with a movie that dares to show how little support there is for people and families dealing with Autism issues in Australia. “The Black Balloon” has been awarded the Glass bear at the Berlin Film festival’s Generation Sidebar.

What is dysfunction? This film tries to show that while obvious differences are seen as dysfunctional (a family with a son who has autism and how it affects each individual) there is a more subtle dysfunction of society at large.

I would warn people who live with autism daily that some scenes are confronting, even if this isn’t your ‘version’ of autism there are parts that will strike a cord and stay with you for days to come. Will anyone listen to the need portrayed here? Let’s hope so.

Outstanding performances by the cast make for a movie which allows the suspension of disbelief wash over you. No glamour, a fairly corny end scene, but empathy and the need for it is highlighted. It would be nice if people were as accepting and kind as Gemma Ward’s character, maybe this is the start of some education for people that there are many differences that can be accepted.

Vicki

Letter about students with autism

A4 wrote to the Hon. Julia Gillard, Deputy Prime Minister and the Minister for Education, about the Tender for the “education” element of the Government’s *Helping Children with Autism* package ... and some other issues.

The letter A4 sent says:

Members of Autism Aspergers Advocacy Australia (A4) are concerned that DEEWR will award contracts in the Government’s *Helping children with autism* (HCWA) package in a way that does little to address the needs of children with autism. A4’s particular concerns are that RFT PRN 17700:

- is about “Inclusion” and “Inclusive Education” so it fails to address the needs of many children with autism,
- fails to recognise or address the needs of students with autism in special schools,
- should but does not involve grassroots representation (people with a diagnosis and parents/family/carers) in decisions and monitoring, and
- will promote incomplete information, possibly propaganda and misinformation, to parents/families of school-age children with autism spectrum disorders (ASD).

Another concern is that the HCWA package does so little for students with autism. Almost all the students currently in schools missed out on the early intervention they needed and are at severe disadvantage because of it. Many others are not diagnosed in time to access

early intervention. The various education systems in Australia are not equipped to meet the needs of many of these students. We ask the Government to recognise and address their needs in education and subsequently in relation to employment.

It goes on to explain the issues in more detail. You can download the letter from <http://www.a4.org.au/documents/JG080228.doc>.

In The News

<http://www.theage.com.au/articles/2008/02/22/1203467395731.html?page=fullpage>

The article *Let's define 'learning disabilities' at last* may interest your readers

Surely the federal government should act immediately to ensure staff employed in education systems across the country can meet the needs of children with learning difficulties and learning disabilities, including most children with ASD. What is the federal government doing to address this challenge?

(Sent by Ian R)

Teen Hacker bypasses anti-virus programmes

<http://www.news.com.au/technology/story/0,25642,23466456-5014239,00.html>

Tragic deaths of people with autism and a paid carer

ATAC media release <http://melbarant.com/atac/latestmedr.html> 16/3

AUTISM CAMPAIGNER SAYS THE TRAGEDY AT CLIFTON BEACH YESTERDAY HIGHLIGHTS THE TOTAL LACK OF ADEQUATE SERVICES AND A TOTAL LACK OF KNOWLEDGE WITHIN GOVERNMENT SERVICE PROVIDERS FOR THE CARING OF AUTISTIC CHILDREN IN TASMANIA.

ROGER LAW, Secretary of **ATAC**, ([Action For Tasmanian Autistic Children](http://www.actionfortasmanianautisticchildren.com.au)) said today that the tragedy at Clifton Beach highlighted the total lack of services for children with Autistic Spectrum Disorder in Tasmania, and the lack of qualified and knowledgeable professional help for families with autistic children.

Mr Law said that on Friday afternoon, he and the missing boy's mother had been with the Commissioner for Children and had raised with him the appropriateness of housing two seriously disturbed autistic children, who did not like each other, in the same unit.

Mr Law queried why only one carer was left to look after these two very seriously disturbed autistic children, neither of whom had the capacity for language. Mr Law said he understands that the normal practice was for two carers to be rostered when both boys were present in the unit. He questioned whether this was a case of budget considerations getting in the way of best practice for vulnerable children in care?.

Roger said he had no criticism of the Carer involved, who was known to him, and whom he had trusted to give respite for his own autistic grandson. He was a strong gentle giant of a man whom it appears was placed in an impossible situation by his employer and who [apparently] gave his own life trying to protect a seriously disabled child.

Hopes fade for missing Clifton Beach swimmers

<http://www.news.com.au/mercury/story/0,22884,23387659-5007221,00.html> 17/3

THE search for a 15-year-old autistic boy and his carer feared drowned at Clifton Beach on Saturday continues, but police say it is almost impossible they will be found alive.

Marine Police Sergeant John Pratt said there was still one police boat searching the water and foot patrols were still being conducted along the foreshore. ...

The severely autistic boy was placed in care by his desperate mother six months ago after she became unable to control him.

The boy, who was also epileptic, and his carer Brendan Dermody went missing from the northern end of Clifton Beach on Saturday afternoon.

No one witnessed the incident, but it is thought the pair were swept out to sea by one of the strong rips commonly found along the beach.

Actually, it appears the incident was seen by the other of two boys with autism who was on the beach ... but people with autism just don't count, it seems (ed.).

... Action for Tasmanian Autistic Children secretary Roger Law said the incident highlighted the "total lack of services for autistic children in Tasmania". ...

Mr Law, who acts as the mother's spokesman, said he could not understand why only one carer was placed in charge of the two boys.

No sign of disabled teen and carer

<http://www.news.com.au/mercury/story/0,22884,23384607-922,00.html> 18/3

Disabled boy and carer presumed dead

<http://www.news.com.au/mercury/story/0,22884,23394452-921,00.html> 18/3

Tragedy 'up to coroner' <http://www.news.com.au/mercury/story/0,22884,23394462-921,00.html> 18/3

IT is up to the coroner to decide whether one carer was enough to supervise two severely disabled children on a beach, says children's commissioner Paul Mason.

Mr Mason yesterday praised the carer, Brendan Dermody, 27, for allowing the disabled children out of the house but said the outing had become a tragedy for many families. ...

System failed our mate, say carers

<http://www.news.com.au/mercury/story/0,22884,23400991-3462,00.html> 19/3

CARERS for high-needs children have described a broken and penny-pinching system that failed their friend Brendan Dermody, thought to have been drowned in huge seas off Clifton Beach. ...

It is thought the pair were swept out to sea, leaving their companion, a 10-year-old autistic boy, alone on the beach.

It is understood the child, who is too disabled to speak, was pointing out to sea when found and the missing teenager's shoes were on the beach along with some of Mr Dermody's possessions.

Carers yesterday described Mr Dermody as a passionate man who had cared deeply and enriched the lives of the children he looked after.

They also said the missing teenager had improved greatly under his supervision.

But Mr Dermody's colleagues also spoke of feeling let down by a "penny-pinching" Child and Family Services that was reluctant to roster adequate staff due to overtime bills. And they said calls to a 24-hour help line often went unanswered.

"No worker should have been placed in the position Brendan was," one carer said.

"There always should have been two carers on."

Child and Family Services director Mark Byrne has said it was felt one carer was sufficient for the two boys and it was quite normal for them to go to the beach.

But yesterday carers said another person had been rostered to help Mr Dermody on Saturday, but had been pulled away to another home.

A contrary opinion

This story started with Tasmania's seriously inadequate services (see <http://www.news.com.au/mercury/story/0,22884,22371788-5007221,00.html>). This situation is a result of grossly inadequate treatment and support for "the single mother-of-three could not get help at home" and her son whose severe clinical disability the government failed to offer appropriate treatment.

Children who are severely disabled by their autism need reliable decisions that ensure their safety whenever they are in care. The Children's Commissioner's suggestion that **"IT is up to the coroner to decide whether one carer was enough to supervise two severely disabled children"** is utterly appalling. That is much too late to be making such a decision. The suggestion is completely abhorrent.

And it is completely inappropriate for the Commissioner to "praised the carer ... for allowing the disabled children out of the house" with demonstrably inadequate safety provision. We fully understand the notion of "dignity of risk" and similar bureaucratic excuses. In order to use these excuses, the government needs to show first that these children made an informed choice ... but this is quite unlikely.

Clearly, disability services are out of control in Tasmania. The children with autism and the carer should not have been anywhere without the required second carer present. Simply, Child and Family Services director Mark Byrne is wrong, wrong, wrong!

Previously profound long-term inadequacies prompted an "Inquiry into Disability Respite Care for Children" (see <http://www.childcomm.tas.gov.au/docs/inquiryintodisabilityrespitecareforchildren.pdf>). This comes on top of reports that ...

NEW allegations have emerged of physical, verbal and emotional abuse in a government disability home.

Last year nine government disability group homes were closed because of serious systemic problems.

In the homes, maggots infested a young brain-injured man's feeding tube and a quadriplegic man's broken leg was not noticed for several days. ...

(see <http://www.news.com.au/mercury/story/0,22884,21004374-3462,00.html>).

Such problems are national, they are cultural: they are not restricted to Tasmania.

Recently, Jack Sullivan, a teenager with autism, from the ACT, died after he was found submerged in a bath in respite care. Jack's story has not been reported in the media. Jack was a relatively prominent member of the ASD community: the (autism specific) Woodbury School in Sydney is named after Jack's mother who for years has vigorously expressed concern about her son's safety when not in her personal care.

But economists and the like, with no specific knowledge of autism, decide what is safe and what is not safe for people with autism. Bureaucrats love saying parents/families know their child better than anyone ... but the bureaucrats just ignore what relatives (and other "experts" including paid carers) tell them about needs and safety while a person is in funded support. Far too frequently, bureaucratic decisions about resources have fatal consequences for people with autism ... and now for a carer as well.

ATAC

Action for Tasmanian Autistic Children].

Tasmania's policies for children with intellectual disabilities lie in ruin" claims ATAC.

Roger Law, Secretary of ATAC [Action For Tasmanian Autistic Children], said today that ten years after de-institutionalisation took place in Tasmania, the failure to introduce programmes for children with intellectual disabilities has brought about a total crisis for hundreds of families in Tasmania.

He stated that today we have deteriorated to the point where before the Coroner has been able to report on one death of an autistic youth last year, another one dies unnecessarily, and a further inquest is required. And we are asked not to discuss the death because it may prejudice the enquiry.

Mr Law said that **ATAC** was meeting with the Minister for Education on THURSDAY 27th MARCH, and that families with autistic children from all areas of the State will be telling the Minister of their dissatisfaction with the services being offered to their children.

Mr Law said that after the meeting a press conference would be held at 90 Argyle Street, Hobart at 4.30pm to 5.00pm to announce any progress that is made in the talks held with the Minister.

ATAC'S WEBSITE ADDRESS: <http://www.atacc.biz/atac> <http://www.melbarant.com/atac>

C.A.T.S

Children's Assessment and Therapy Services (**C.A.T.S**) is a family centred service that takes a multi-disciplinary approach. C.A.T.S is made of three established paediatric practices that specialize in ASD including Fiona Martin (Child Psychologist); Mosman Language & Learning Centre and Beverley Clarke Occupational Therapy Services. C.A.T.S is proud to announce two workshops on Autism Spectrum Disorders for 2008:

- 1). Monday 2 June 2008 held in Sydney for **Preschool teachers and support staff**
- 2). Wednesday 18 June 2008 held in Sydney for **Primary school teachers and support staff**

The workshops will cover a range of topics including diagnostic criteria, and associated features, screening, early intervention, access and funding, practical strategies for learning, behaviour and social-communication development, school readiness, and issues to consider when choosing an educational setting. The workshops are interactive and encourage the application of knowledge. You will be given case studies and asked to apply your knowledge and skills. The workshop will end with a panel discussion (psychologist, speech pathologist, occupational therapist and early intervention specialist) where there will be an opportunity to ask specific questions and discuss cases and issues. Participants will receive a training kit which will include handouts and practical applications of the course content. A resource table will be set up for participants. **For further information contact Fiona Martin, Child Psychologist Tel: 0407 400 159 or Mosman Language & Learning Centre Tel 02. 99684075**

Research and Information

Autism Expense

New research suggests that the average household with children with autism not only spends thousands of dollars toward educational, behavioural and health care expenses each year, but also suffers from a lesser-known cost that hits them up front – a sizeable chunk of missed household income, perhaps as much as \$6,200 annually.

The study, published in April's edition of *Paediatrics*, paints a more detailed financial picture of how expensive life can become for parents of children with an autism spectrum disorder.

"To our knowledge, this is the first U.S. study that examines this front half of the 'money in, money out' equation," said economist **Guillermo Montes, Ph.D.**, the study's lead author and a senior researcher at the Children's Institute, a not-for-profit organization affiliated with the University of Rochester, where he also serves as a faculty member in the division of General Paediatrics. "To collect data on expenses is fairly straightforward- it's a survey report. But projecting earning potential and then stacking that against actual income requires complex statistical modelling."

The fill press release is <http://www.rochester.edu/news/show.php?id=3144>

Other references are at

<http://google-sina.com/2008/04/02/households-with-kids-with-autism-likely-to-earn-less/>

<http://www.medicalnewstoday.com/articles/102520.php>

Seminar

The La Trobe University School of Law and the Michael J Osborne Centre - Institute of Advanced Study invite you to attend the following seminar.

The meaning of equality in law: decisions related to the sterilization of people with disabilities

This paper will consider legal decisions related to the sterilization of people with disabilities in England, Canada and Australia. It will focus on the social and legal construction of the concept of equality.

1.00 pm Monday 14th April 2008

Seminar Hall

Michael J Osborne Centre - Institute for Advanced Study

(Melways Ref: Map 573, f1)

Guest Speaker: Professor Marcia Rioux

Professor Marcia Rioux is a La Trobe University Distinguished Visiting Fellow sponsored by the Faculty of Law and Management and the School of Law. Marcia has a Ph D in Jurisprudence from UC Berkeley and is a Professor in the School of Health Policy & Management at York University, Canada. She is Director of the York Institute of Health Research and Graduate Director of the Program in Critical Disability Studies.

For further information please contact:

Julia Anderson - phone: (03) 9479 3461 or email: j.anderson@latrobe.edu.au

Michael J. Osborne Centre- Institute for Advanced Study

Baron-Cohen

The UK has its Autism Research Centre (featuring Ali G's less famous brother, Simon Baron-Cohen, see http://www.autismresearchcentre.com/arc/staff_member.asp?id=33) getting major funding from government through the Medical Research Council.

The US Government continues to expand its investment in autism/ASD research (see <http://www.medicalnewstoday.com/articles/102543.php>).

Where is Australia's effort? Nowhere to be seen. Australia needs to fund ASD research or we will not be training and maintaining skills in professional staff needed to treat and support

people with autism in this country. The state of ASD research in Australia, primarily due to the absence of funding and leadership, is a sick and not-funny joke.

It is time for the federal Government lifted its game in autism/ASD research significantly.

ABS

It is estimated 1 in 118 children are diagnosed with autism. ABS says that there were 424,073 children aged 0-4 in Australia in 2005 NSW has 30% of the Australian population which equates to 106,018 children under 4 in NSW in 2005.

106,018 0-4 year olds births means and 1 in 118 being diagnosed that 2,600 of these 2-6 year old children will have a diagnosis of autism – somewhere on the spectrum. Births are escalating.

2,600 children are currently within the funding target of 2-6 years at this time. The funding package will provide direct support to at least 660 children between the ages of two and six over the next four years. This is an average of 165 children per year for 2,600 children, many who will need these services, some who already have very limited intervention. The DVD might be very beneficial to the 10,435 who miss out on services and interventions cause they won't be getting much else.

Media release says the services include:

\$1.24 million for a child-care centre in Western Sydney to help children with autism attend mainstream schools without the use of an aid;

\$2 million for the rollout of 20-week targeted programs for preschool aged children;

\$2 million to provide centre-based and home-based services by special education teachers and therapists;

\$500,000 for the University of Newcastle to provide training to front line staff who work in early childhood intervention services; and

\$200,000 for the rollout of a DVD and manual to help families of a young child immediately following their diagnosis of autism.

United Nations called on for Autism

Ivan Corea of the UK Autism Awareness Campaign calls on the United Nations on World Autism Day to open every door for children with autism. See the internet videos at

<http://edition.cnn.com/video/#/video/health/2008/04/02/intv.austism.corea.cnn> and

<http://ukautismnews.blog.co.uk/2008/04/04/un-world-autism-awareness-day-you-tube-f-3994549>

Certainly we need the world to recognise the needs of people with ASD because our national and state governments refuse to adequately address the needs of people with ASD.

YDAS Shorts – Short Films By and About Young People with Disabilities

A National Youth Week Event

Last weekend in Melbourne there was a première screening of "It's a Blind Chick Thing", a new short documentary that follows the story of a 19 year old 'blind, Italian, Egyptian, Muslim stand-up comic' who travels her way to New York for the gig of a lifetime.

There were also live readings of short film screenplays that promote issues and experiences of young people with a disability. An open forum followed which facilitated discussion about the representations of youth and disability in film.

With so few people having their own voice in mainstream media this was an outstanding achievement; please forward any events like this on to the editing team here at A4.

Some YouTube and other internet links

What is awareness anyway?

<http://aspengersquare8.blogspot.com/2008/03/what-is-awareness-anyway.html>

Temple Grandin

<http://www.youtube.com/watch?v=bgEAhMEgGOQ>

Letters to the Editor

Hello Bob,

Inclusion and Autism – my favourite subject. NOT. I will try to be brief. It is an absolute nightmare and not getting better for us in WA.

Inclusion and ASD does not work and never will. I really enjoyed reading that ASD should be regarded as a separate disability when talking about inclusion and education. YES it should be because YES it is. A blind student (i.e. is disabled and needs to be ‘included’) is different to a Deaf student (ditto) and different to a cerebral palsy kid, different to an intellectually handicapped kid and is different to a child on the ASD spectrum and then different again to a child with high functioning autism. Yes they are all bunched in together, called kids with disabilities and special needs and are “included”.

Physical Presence in a school setting is not inclusion. Schools are not succeeding by saying “Look, we are an inclusive school – we have special needs kids attending here”. Hello! It takes a lot more than that. Chucking an ASD child into a school community and making them endure the difficult and terrifying day is not inclusion. But this is what happens in real life.

Professional Development is pathetic. We have a senior teacher – who tells us point blank “I don’t need any training as I have had an autistic child before”. Full stop end of story. Senior teacher in a public school – there is no accountability – she can do what she wants. Thankfully for us, this teacher is listening to us about other things.

We are unlucky. Unlucky because my ASD high functioning child does NOT act out at school. God how I wish he would hit the other kids, hit a teacher or two, spit, swear, punch or throw a few chairs. NO – he just endures what they make him do – he sits there in fear and absolute terror then comes home and terrorises us all night long as he tries to process the stress and anxiety of his day. We then patch him up and send him again the next day.

Can we move schools? In theory yes; in reality No. He cannot attend a special ed unit (IQ too high), most other mainstream schools around us are full and not accepting any children – and moving to another mainstream means more of the same crap. Private schooling – possibility – but then there is less funding and more difficult to get teacher assistant time and again the school placement is a raffle.

My child needs a bit of mainstream (the good bits for him) and a bit of something else. The something else could be home-schooling, distance ED, or a special ed unit. But – this is not allowed in WA at the moment – unless your principal approves (he refuses), district office approves and I think the minister has to endorse it. As if this is going to happen.

My child is not normal. Never will be but they treat him as if he is normal and he is made to sink or swim. He gets little special treatment (he needs tons). He needs a flexible education system – ours isn’t.

I just endure every school day, every school week and every school term. Our job as parents is to manage the backlash and the meltdowns we get daily as he de-stresses.

None of this happens during the Xmas school holidays....it is only school that does it to him.

I know many other mums of ASD kids in WA who feel the same as I do. I know that I am not alone.

I don't mind parts of this email being reproduced – but I do need to protect my identity. My child still has to attend this school and he has a younger brother in kindy. I want to shout my story from the rooftop, go to the media, get in print – but I have 2 children still having to go thru this school and the backlash from my opinions will cause too much irreversible trouble. So please be circumspect in how my opinions are portrayed.

Thanks and keep up the great work.

L.

Dear Mr.Buckley,

I am concerned about adding my name to the "1000 hours" petition.

I have experienced the importance of early intervention, the prohibitive(to most families) cost of the intensive therapies which can help children exhibiting aspects of autistic/autistic spectrum behaviours. I have had to wait on long waiting lists to access public services. I know how lonely it is being a parent of a child "who does not fit in" and I know how hard it is to work constantly with your child to help them speak, move, touch, experience and be with other people (so much so, his speech therapist said I had to ease up because I had ceased being a parent because I was viewing everything he did through the eyes of a therapist). I do not want other parents to experience this hardship and I want other children like my son to benefit from early intervention.

However, I am concerned about where the money will come from to fund the 1000 hours for each child, to pay for the many new therapists needed to provide this type of intervention (I might also ask where the people will come from since there is such a manpower shortage in almost every profession and trade, but that is another issue), and to pay for all the professionals who will make the official assessments/diagnosis of each child who is to receive the 1000 hours.

I am also concerned about the criteria which will be used to decide who will receive the 1000 hours. This is an expensive programme/plan which will be controlled by a government department it seems inevitable that efforts will be made to 'triage' the criteria just to keep cost down. Look at public hospitals anywhere to see this in action. I worry efforts may be made to exclude older children/teenagers from access to these programmes because they will not show the same rate of improvement and may be viewed as "a waste of resources". I am concerned parental participation (active participation requiring the parents to work at home with the children in an intensive way) may be a requirement for the children to access this plan, which could cause many parents to choose not to proceed because they are afraid or daunted by the work involved and the impact on their lives - other children, social and work commitments and marriage.

I want to sign the petition because I want our government to provide resources to help families with children who need extra support. However, I don't want to sign a petition for a programme which may look good and may make good headlines for politicians, but which fails to deliver real, long term benefits for all, or most, who need the help.

Yours sincerely Justine Martyr

Dear A4 Committee

Just thought would write to thank you for your ongoing commitment and send you a brief outline of my frustration at the moment.

Our lovely little boy is 6 and attending a mainstream school here in Brisbane. It is a state school we chose over the original private school because it has an autism unit. I have asked all year how is he going during lunch breaks and all they can tell me is that they would have heard something if there was something to hear. Then the very week I start full time work (after a 7 year hiatus - needed because of added financial demands) I hear from the school that Clay is not coping with lunch time play and hitting out at kids in social situations to get their attention. Aaaaarrrrrggggghhhh. I have told them before that if he sees this behaviour in the playground he will consider it appropriate and at the same time has brought swear words into our home also. Now Clay is not conniving so does not understand that you don't swear when you can be caught and that you don't hit out when teachers are watching. (we all know it goes on behind backs.) So the best this school can do is bring him into the autism unit during lunch breaks. They say it is not punishment and he is free to choose his activities after he eats lunch. These activities are very limiting when indoors. However, he is denied the opportunity to learn social skills and run around burning up energy. Then he is expected to go back to the class room and sit still at his desk and not be disruptive in the classroom. I just can't seem to get them to understand that they are really setting him up to fail. Added to this stress is my inability to visit the school to discuss it and to rely on the teachers being available when I have my lunch break because I can't make private calls during work time.

My husband and I have made many sacrifices to get Clay to a mainstream school which also include selling our home to finance early intervention and keeping me at home for as long as possible. Now we feel that all the hard work will go to waste and he is at the best school - in the area - to service his needs.

Thanks

Laura Lewis. Brisbane, Qld

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.

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