UPDATE

A4 Autism Aspergers Advocacy Australia

December 2007
Issue 8

Autism Friendly Christmas

Tips for the eccentric or spectrum person by Donna Williams

The Christmas tree looks best when standing inside of the branches looking out through the lights.

- Don't forget to tap the decorations, they sound good too.
- Shiny decorations are wonderfully lick-able (but don't eat them).
- Glitter doesn't taste anywhere near as fantastic as it looks (what a mystery).
- There is actually something under the paper.
- Decorations are a far greater buzz when people want them put back on the tree.
- Christmas lights are best viewed through a strand of tinsel.
- We can all be Santa.

Inside this Issue

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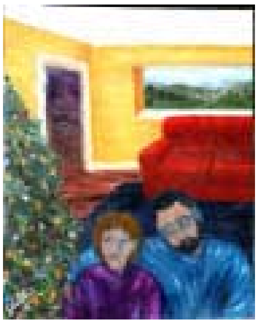
- Giving starts with what's invisible.
- The best Christmas gift is the genuine smile at one's own reflection.
- If nothing else, dare to whisper/hum/sing/type just for Christmas.
- Gifts are best appreciated in one's own space.
- The cat often can't eat well with people watching.
- You can make 'snow' from pretty much anything.
- Dressing up in tinsel makes you shine.
- Peace is having your neurotransmitters working for you at Christmas.
- Happiness isn't mania; I'd rather smile like Mona Lisa than grimace like Cheshire Cat.
- I resolve in the New Year to BE and DO and SEE and and and and.... to calm down and chill out and actually keep up with myself (writing, art, sculpture and music composition are all acceptable artistic exceptions).
- I resolve to remember how lucky I am, to live in the moment, to walk the middle path (loving all my yuck and fabness equally as self acceptance), to love but not co-dependently, and to know that those mountains are really just molehills under a microscope.

So when that time of year comes around, Merry Christmas everyone and a wonderful, empowering, self owning, simply be New Year to you all.

http://www.donnawilliams.net http://www.auties.org



Thank you to Donna for sharing her Christmas thoughts with us, for more information on Donna's work and life please follow the links to her sites.

From the A4 Steering Committee

A4 Update editor resigns

We are saddened to say Juanita has resigned from her role as one of A4's Update editors. Juanita has been an integral part of the editing team since November 2005. A4 owes a substantial debt of gratitude to Juanita for her work in this role: it is a large job that is never easy; Juanita was a hard working and valuable editor and will be sadly missed.

This leaves Vicki as our sole editor. Editing A4 Updates is a big task. The best help would be for as many people as possible to provide material for the A4 Updates. Please write to Vicki at editor@a4.org.au with any ideas or information you may have to make the newsletter both informative and interesting. Members are welcome to share positive and negative stories about their Autism journey. The newsletter can also be used to alert members to supports which exist in specific states which are not well known. Write to us now, share your information.

Steering Committee invitation

Over the last 12 months, several people left the A4 Steering Committee. This leaves plenty of space for new people with new ideas and perspectives to help shape our direction.

The Steering Committee is a key to A4's success. Currently the A4 Steering Committee operates via an online discussion that guides A4 in what it does. It decides what issues A4 gets involved in and how A4 lobbies government.

You can be part of the group that decides what A4 does and how it goes about its business.

You do not need experience or expertise in any specific area; we are looking for intelligent people who can work together on a team to advance the needs of those within our community. If you have skills that you would like to share please apply, there are roles in reporting, lobbying, web design and more. A4 needs your opinions, skills and ideas. It needs your suggestions and constructive criticism to guide its activity. We are keen for people who are interested from all over the country to be part of this important group.

We would also like to encourage 'grassroots' input from those of our A4 community who are not usually heard from. They are often the most vulnerable whose needs are the greatest. These voices are definitely needed.

If you are interested please email the Convenor (cnvnr@a4.org.au) your contact information and a few paragraphs about yourself and your interests in autism, Asperger's or PDD-NOS.

Asperger's Syndrome Gets a Very Public Face

By TARA PARKER-POPE

Heather Kuzmich has the neurological disorder known as Asperger's syndrome. She is socially awkward, has trouble making eye contact and is sometimes the target of her roommates' jokes.

But what makes the 21-year-old Ms. Kuzmich different from others with Asperger's is that for the past 11 weeks, her struggle to cope with her disability has played out on national television.

She is one of 13 young women selected by the supermodel Tyra Banks to compete on the popular reality television show "America's Next Top Model." The addition of Heather Kuzmich to an otherwise superficial show has given millions of viewers an unusual and compelling glimpse into the little-understood world of Asperger's.

The disorder, considered a form of autism, is characterized by unusual social interaction and communication skills. Aspies, as (*some - ed*) people with the condition like to call themselves, often have normal or above-average intelligence, but they have trouble making friends and lack the intuitive ability to gauge social situations. They fail to make eye contact and often exhibit a single-minded fixation that can be both bizarre and brilliant.

By definition, people with Asperger's are outside the mainstream. Even so, in recent months the syndrome has been cast into the limelight. "Look Me in the Eye," a memoir about living with Asperger's by John Elder Robison, who once created special effects for the rock band

Kiss, has been a best-seller. In August, the Pulitzer Prize-winning music critic Tim Page wrote a poignant article for The New Yorker about life with undiagnosed Asperger's.

Mr. Robison says the popular appeal of these stories may be due, in part, to the tendency of people with Asperger's to be painfully direct — they lack the social filter that prevents other people from speaking their minds.

"It's important because the world needs to know that there are tremendous differences in human behaviour," said Mr. Robison, whose brother is the writer Augusten Burroughs. "People are all too willing to throw away someone because they don't respond the way they want. I think books like mine tell the world that there is more to us than that."

But while Mr. Robison and Mr. Page tell the story of coping with Asperger's from the perspective of men in their 50s, Heather Kuzmich is just beginning her life as an adult with the disorder. And it is often painful to watch her transition from socially awkward adolescent to socially awkward adult.

A gifted art student from Valparaiso, Ind., she has a lean and angular look well suited to the fashion industry. But her beauty doesn't mask the challenges of Asperger's. The show requires her to live in a house with 12 other would-be models, and cattiness and backbiting ensue. Early in the show, she appears socially isolated, the girls whisper about her within earshot, and viewers see her crying on the phone to her mother.

One girl is frustrated when Heather, concentrating on packing a bag, doesn't hear a request to move out of the way. At one point, the others laugh when they stake out their beds and Heather has no place to sleep.

"I wish I could get the joke," Heather laments.

"You. You're the joke," retorts another model, Bianca, an 18-year-old college student who is from Queens.

But while Heather's odd mannerisms separate her from her roommates, those same traits translate as on-the-edge high fashion in her modelling sessions. In interviews on camera, she often glances to the side, unable to hold eye contact. But Ms. Banks, the '60s-era model Twiggy and the fashion photographer Nigel Barker, who all appear on the show, marvel at Heather's ability to connect with the camera. The pop star Enrique Iglesias is so taken by her haunting looks that he chooses her for a featured role in a music video.

In an interview last week, Ms. Kuzmich played down the conflict with the other contestants, saying many more "civilized" exchanges weren't broadcast. "They didn't make fun of me that much," she said.

She tried out for the show, she explained, partly to test her own limits. "It was a point in my life where I was thinking either Asperger's was going to define me or I was going to be able to work around it," she said.

To her surprise, she was voted the viewer favourite eight weeks in a row, making her one of the most popular contestants in the show's four-and-a-half-year history. "I'm used to people kind of ignoring me," she said in the interview. "At first I was really worried people would laugh at me because I was so very awkward. I got the exact opposite."

Heather made it to the top five, but flubbed her lines while filming a commercial. Later, she got hopelessly lost in Beijing, managing to meet with only one out of five fashion designers. She was eliminated last week, but has since made appearances on "Good Morning America" and "Access Hollywood." She says she hopes to continue modelling and eventually become a national spokeswoman for Asperger's.

"I had no idea it would be this big," she said. "My mom is beside herself. She watched me when I was a kid not have any friends, and she saw me struggle. She's glad people are starting to understand this."

well@nytimes.com

Lost boy killed playing on railway tracks in Essendon

Anthony Dowsley and Geraldine Mitchell December 10, 2007 12:00am

A SEVEN-year-old boy playing under a railway station platform has been struck and killed by a train.

The Essendon boy, believed to have autism, disappeared from his father's house about 7am yesterday still wearing his pyjamas.

He had wandered to the Strathmore railway station and was seen playing on the tracks when a city-bound V/Line express hit him.

The incident happened shortly before 8am, minutes after the boy's father contacted police to report him missing.

An elderly man on a morning walk saw the boy on the tracks and warned him to get back on the platform.

He noticed the train approaching and frantically tried to warn the driver to stop.

"He was walking along the railway lines. I actually saw him on the line and I thought, well you know, he shouldn't be on the line," Ian said.

"Unfortunately by the time I got to him, the train was coming around the bend."

Autism affects the ability of a person to understand the meaning and purpose of body language and speech.

Those with the condition can misinterpret or not comprehend people speaking to them and also their feelings and emotions.

It is understood the driver, travelling from Seymour to the city, saw the boy and applied the brakes but could not stop in time.

The train had just rounded a bend and the driver would have had little time to see the boy on the tracks.

Investigators say the train would have been travelling up to 60km/h at the time.

It is not known how far the boy had walked to the train station.

Police first on the scene performed first aid on the critically injured boy but he died before paramedics arrived. A witness has told the police the boy was alone when he saw him.

Moonee Ponds Sen-Sgt Andrea McAlpine said the boy's parents, who are separated, were searching for the child when told of the accident.

"It is just a tragic accident and our hearts go out to the family," she said.

"He was staying at his father's house.

"They are very upset, understandably so, and we hope they have the support of their family at this time."

V/Line spokesman Daniel Moloney said the eight passengers on board were given taxi chits to get to the city from Strathmore.

He said all passengers, the driver and conductor were distressed by the accident and had been offered counselling.

"It's a really horrible situation all round," he said.

"You've got a family who is going through hell and a driver, staff and passengers who are devastated by this."

The line was closed for about three hours and was cleared by 11.30am.

Connex and Victoria Police will investigate the circumstances that led to the death.

Mr Moloney said Connex would lead the rail investigation because the accident occurred on its track.

A report will be made for the coroner. Premier John Brumby struggled for words to describe the accident, which happened just a few hundred metres from his family home at Strathmore.

"It's just a horrible, horrible tragedy," Mr Brumby said. "You just hope it's news you never hear." "It's a seven-year-old boy. He got down on the tracks. He apparently didn't realise he was in any danger."

Our heartfelt sympathies go to the family and friends of this boy on behalf of the A4 community

Convenor's message

Dear A4 member — There is a lot going on at present.

Esperanza sent me a new batch of signed petitions for the Government. You can do this too … get a blank petition page from our website (the URL is www.a4.org.au/documents/EsperanzaPetition.doc) print a couple of them, then get your friends and fellow workers to sign them. Finally post the pages with any signatures to me. I will deliver them to the new Government.

As evidence there is life beyond ASD advocacy, my band released our latest CD (see www.paverty.com.au).

It is such a change to be talking about how services for people with ASD might be done best … rather than trying to convince Government that something needs to be done at all.

Various federal Government Departments are getting on with implementing the Government Initiative for autism spectrum disorders. Since the schedule has the initiative up and running by July 2008, activity is fairly frenetic.

I am especially pleased that staff in the various departments are consulting quite widely. Australia should have more people with expertise relevant to ASD policy to consult. I am optimistic that nationally we can increase expertise in service delivery relatively quickly though we will all need to be wary of instant experts.

A4 still faces important challenges. First is to get Australian Governments to accept that they need spend enormous amounts on autism spectrum disorders. Then we have to convince Government that money they spend could achieve far better outcomes were it spent more appropriately.

So I challenge you to think about what A4 should advise Governments to do next. Once they get their initiative up and running in July 2008, what issues do we want them to tackle next?

Write to A4 and tell us what you think the Government should do next. Of course, you can write directly to Governments as well.

I see very little sign of state governments understanding any of what this is about. It is interesting that the federal Government will roll out a range of services in under 9 months from the announcement … yet state governments who have serious responsibilities for relevant services show little or no sign they appreciate what any of this is about. For example, the Victorian State Autism Plan will take years just to create a state autism plan. And Victoria seems to be ahead of most other states in this regard.

In other news The AABASD decided from 2008 May will be Autism Spectrum Month in Australia. Previously Australia had an annual autism awareness week.

Qatar convinced the United Nations to make 2nd April World Autism Day (see http://www.autismspeaks.org/press/qatar_un_world_autism_day.php).

By the time you read this, **International Day of Disabled Persons** (3 Dec 2007 – see http://www.un.org/disabilities/default.asp?id=110) will have passed. The theme this year is

"Decent work for persons with disabilities". I expect there will be free lunches in the ACT around this but I see no sign that it will help anyone with ASD into "decent work". The ACT Government is blind to the needs of people with ASD.

What is this "persons with disabilities" phrase? Surely they are people too? Simply, "person" is an irregular noun: in the English language its plural is "people" (see http://grammar.ccc.commnet.edu/grammar/plurals.htm). Some relevant discussion occurs at http://apastyle.apa.org/disabilities.html … which is confusing since it often uses "persons" but gives rules and examples saying "**1. Put people first, not their disability**" and "**2. Do not label people by their disability**". I am so over pointless language mutilation allegedly to further political correctness. Down with "persons" … I want outcomes for *people with ASD*.

In USA, presidential candidate Hillary Clinton says she will inject a further $700 million per year into autism education and research (see http://www.autismspeaks.org/press/clinton_speech_response.php and http://www.nytimes.com/aponline/us/AP-Clinton-Autism.html). She recognises that autism costs the US at least $35 billion per year.

Australia needs to spend much more on autism/ASD research. We should follow the US lead in this respect.

Just when I thought debate had settled down a little on how many people have an autism spectrum disorder, I come across some different views.

A discussion of autism/ASD prevalence in the US makes an argument that ASD prevalence in the USA is 1 in 67 rather than the oft-quoted CDC rate of 1 in 150 (see http://www.vaproject.org/yazbak/1-in-150-is-really-1-in-67-20071005.htm).

A section from the recent report entitled the *Economic consequences of autism in the UK* (see below) says:

> **Prevalence estimates**
>
> Estimates of prevalence were sought from the literature, and from leading epidemiological experts in the autism field. We were unable to influence the ways in which previous prevalence studies categorised the population, whether in terms of age groups or diagnoses, and therefore had to use what was available and then try to marry those available prevalence estimates with information from other sources that would allow us to attach costs. We have, as far as possible, relied heavily on the most recent estimates available.
>
> The estimates suggested from the literature and from expert advice are as follows:
>
> - The most recent published estimate is offered by Baird and colleagues, (2006) who estimated the prevalence of autism among 9-10 year olds in South-East England to be 38.9 per 10,000; other ASDs as 77.2 per 10,000 and all ASDs as 116.1 per 10,000. This is at the high end of the range of prevalence estimates.
> - The overall prevalence estimate for children aged 5-16 from the national survey of the Mental Health of Children and Young People in Great Britain, conducted in 2004, was 0.9% (Green *et al*, 2005).
> - Eric Fombonne, (2005) offered 'conservative' estimates of 13 per 10,000 for autistic disorders; 20.8 per 10,000 for PDD-NOS; 2.6 per 10,000 for Asperger's syndrome; and 36.4 per 10,000 for all PDDs.
>
> For our calculations we use a prevalence estimate of 1% across all ages, which is slightly lower than the figure from the recent Baird study, but is the figure recommended for our "all-ages" approach by Tony Charman (personal communication).
>
> Baird G, Simonoff E, Pickles A, Chandler S, Loucas T, Meldrum D, Charman T (2006) Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). Lancet, 368, 210-215.
>
> Green H, McGinnity A, Meltzer H, Ford T, Goodman R (2005) Mental health of children and young people in Great Britain, 2004. Office of National Statistics.
>
> Fombonne, E (2005) Epidemiology of autistic disorder and other pervasive developmental disorders. Journal of Clinical Psychiatry, 66 (Supplement 10), 3-8.

And in Australia, some Government agencies are inclined to severely underestimate the effect of autism spectrum disorders. Politicians and bureaucrats are inclined to believe “high functioning autism” means high functioning (with little or no disability) … and that people get over “childhood autism” when they become adults.

The AIHW report, *The burden of disease and injury in Australia 2003* (May 2007) AIHW cat. no. PHE 82 bases its results on questionable prevalence data. It says …

> Autism is part of pervasive developmental disorders; the other important condition in that category is Asperger’s syndrome, which was described at about the same time as autism. Autism is characterised by the triad of language or communication impairment, social impairment and behavioural impairment (obsessions, rituals). However, Asperger’s syndrome has only the latter two components and is not associated with intellectual disability, as is the case with 80% of autistic children. Behavioural problems are a predominant feature in children with Asperger’s syndrome.
>
> We derive the incidence of autism and Asperger’s syndrome from an Australian study with data from treatment and educational support services in Western Australia and New South Wales. We assume no remission and an elevated risk of mortality as reported by Shavelle and colleagues (2001). We use the average duration of mild intellectual disability and the Dutch disability weight of 0.55 for autism, and for Asperger’s syndrome an estimated weight of 0.25 based on expert advice that the condition is worse than moderate to severe attention deficit with hyperactivity disorder but much less severe than autism.

Despite basing the model on a conservative incidence level[1], the report ranks autism spectrum disorders

- 15th for males in terms of **Table 3.4: Leading causes of incident non-fatal burden (YLD) by sex, Australia, 2003** (page 46)
- 2nd for boys and 8th for girls in terms of **Table 3.6: Leading causes of DALYs in 0–14 year olds by sex, Australia, 2003** (page 48).

The AIHW would describe ASD as having a larger impact if it used more recognised prevalence estimates for ASD in its modelling. In turn, this could motivate Australian governments to respond more comprehensively to the challenge that ASD presents.

Increasingly, I feel authorities in Australia need to plan for ASD prevalence between 0.7% and 1% of the population born since 1990. This is a higher rate than is generally recognised in Australia.

It seems likely that fewer than 35% of people diagnosed with an ASD could be assessed as also having an intellectual disability. Reports describe people with ASD as having high rates of severe or profound disability yet many of them are excluded from crucial services because the services are provided for (limited to) people with intellectual disability.

I will end this message wishing you all a joyous festive season. For those of you who are not feeling joyful at this time, I hope my suggestions in *Transition and the festive season* below are helpful.

Sincerely
Bob Buckley
2/12/2007

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[1] The “Australian study with data from treatment and educational support services in Western Australia and New South Wales” is probably Williams K, Glasson EJ, Wray J, Tuck M, Helmer M, Bower CI, Mellis CM. (2005b) *Incidence of Autism Spectrum Disorders in children in two Australian States*, MJA, 182(3): pp108-111 (see http://www.mja.com.au/public/issues/182_03_070205/wil10326_fm.html). This paper does not explain adequately how its unusually low incidence figure is derived from its raw data. Note that several of these authors, Williams, Glasson and Wray, subsequently describe the prevalence of ASD in Australia at 1 in 160 in their 2007 report for the AABASD (see http://www.autismaus.com.au/aca/pdfs/PrevalenceReport.pdf). Similarly, my peer-reviewed proceedings paper (see http://autism.anu.edu.au/pdf_files/buckley_submit2.pdf) found much higher prevalence from the same published source data … consistent with prevalence for ASD reported internationally.

Australia's latest Government

The 2007 election gave Australia a new Government. The Ministers now responsible for the Government's autism initiative, and their shadows (see www.liberal.org.au/documents/mediareleases/ShadowMinistry.pdf), are:

	Government	***Opposition***
Families, Housing, Community Services:	Jenny Macklin	Tony Abbott
Health:	Nicola Roxon	Joe Hockey Richard Colbeck
Education:	Julia Gillard	Tony Smith Brett Mason

Expect A4 will also deal with

Prime Minister & Cabinet:	Kevin Rudd	Brendan Nelson
Attorney-General:	Robert McClelland	George Brandis
Human Services:	Joseph Ludwig	Helen Coonan
Workforce Participation:	Brendan O'Connor	Julie Bishop Mr Southcott
Parliamentary secretary to the Prime Minister, Early childhood education and childcare:	Maxine McKew	?
Disabilities and children services:	Bill Shorten	?
Social inclusion:	Ursula Stephens	?

There may be some new rules. A4 may need to register official lobbyists.

Help with the A4 website

A4 is still looking for people to help develop and run a new website. Several people have offered to help develop and moderate content on a new A4 website.

But A4 still needs people who can help with the technical side of a website based on a modern content management system. We need one or more people who can help set up a new website.

Do you want to help or know someone who said they want to help … and who has or wants to develop internet technical skills? We can help them learn as they go if they are interested. At this stage the new site is likely to be based on Drupal, Joomla or some similar system (if you are interested in technical stuff and do not recognise these systems, you can look them up on the internet).

Please … anyone who is interested can email cnvnr@a4.org.au for more information, or to volunteer.

Transition and the festive season

Bob Buckley

Traditionally, one offers compliments of the season at this time.

But for the families of people with ASD the summer holiday season is often a time of transition and major disruption especially for school age people with ASD.

Unfortunately, most schools and education departments just don't get it. They could consider the needs of their students with ASD but they just don't. Their strategy is to maximise pressure on families and students with ASD so they get their way at the start of a new school year.

Where a student with ASD needs to make a transition from one setting to another, even from one teacher to another, schools could organise that the transition is done prior to the long "holiday" so that the student with ASD could return in the new year to a more familiar setting. The school or the Department could organise that transitions for students with ASD are more predictable.

Students in mainstream start their new year with their education plan already established. Many students with ASD have to wait months for their plan to be developed … if it happens at all.

In some enlightened settings (not in Australia) students with ASD who prefer the routine and who need an extended school year continue their education through most/all their summer.

Many students with ASD and their families spend their summer dreading the start of the next school term. They simply don't know what is supposed to happen. They know they will be forced urgently into unsatisfactory arrangements in the new school year.

My advice for people who find themselves in this situation is to:

- address developments through the summer — avoid wasting your energy with regrets over things you can no longer change;
- be clear at the start of the year that you regard arrangements made in haste as temporary and will review them as soon as possible; and
- avoid fighting with the school — take your issues to the district or state office, or to the Minister if necessary.

You could ask your child's current teacher what would work best for him/her next year. They may not think of everything. So you can ask them things like "would he learn more if her/she had support in the playground?" Before the end of this year, write to the school asking for the resources you feel your child needs next year.

If the school says "no" ("we can't do that", "we don't have enough resources", etc.) or does not respond within 2 weeks, do not argue. Do not discuss it further with the school. Contact the special needs section in your district or state education office. Ask for their help: tell them your child needs these resources and that the school said "no" or did not respond. This is about helping the school get the resources they need to educate your child.

It is always best for you and the school (usually through the Principal) to have a shared plan for your child. So you should avoid fighting with the school. If the teacher does not do what you want, don't fight with the teacher — talk to the Principal and get him/her to agree with you. Then get the Principal to tell the teacher what to do. If you cannot get the Principal to agree, go to the next level up (the district or state office). Get them to work on things they agree with … and get someone else (therapist, respite worker, after school care, yourself, … ?) to address areas where you disagree.

If the school complains about your raising concerns at a higher level, you need to ask whether they want to help your child or whether they just want to manage the Government's bottom line.

Please, if you have suggestions how people can best work with school to improve education for children with ASD, write and share your suggestions and advice. It could help people have a merrier summer.

UK Report on Autism costs

A new report entitled the Economic consequences of autism in the UK was released recently in the United Kingdom. The press release says …

> According to new research commissioned by the Foundation for People with Learning Disabilities, the annual cost of autism to the UK is just under £28 billion.
>
> The findings, detailed in the Economic Consequences of Autism in the UK report, reveals that children with autism cost £2.7 billion a year, yet for adults the figure is £25 billion - more than eight times as much. There are approximately 540,000 people with autism in the UK - 433,000 adults and 107,000 children.
>
> http://www.learningdisabilities.org.uk/media/news-releases/news-releases-2007/19-november-2007/

The report is straight forward reading. You can download the report at http://www.learningdisabilities.org.uk/publications?EntryId=28948 The Executive Summary concludes

> **Lifetime costs**
>
> The lifetime cost for someone with high-functioning autism was found to be £3.1 million and £4.6 million for someone with low-functioning autism.
>
> **Relevance of these estimates**
>
> *What makes these new cost estimates so relevant today? There are four broad reasons. In the first place, our estimates span all areas of public sector expenditure, including education and housing, demonstrating not only the high support costs for people with ASD but also the breadth of those costs. Second, this analysis recognises the high cost to families, in terms of out-of-pocket expenses, lost income and lost employment opportunities. We could not include the time costs for family members who care for an individual with ASD, but there is no doubt that these will be considerable. This recognition of the high support costs for ASD leads to two further reasons why these new estimates are important. Firstly, there are early interventions available that help alter behaviour patterns. Would increased investment in these reduce high support costs in adulthood? Secondly, a greater availability of effective early interventions may reduce the impact of ASD on the UK economy as well as improve quality of life for people with ASD and their families.*

On a *pro rata* basis, autism would cost Australia around £9 billion per year. You can consider what the annual cost of autism to Australia is in Australian dollars.

The challenge for the Government is to turn this around to maximise the social and economic benefit of autism spectrum disorders to the nation.

Did Victoria lose sight of ASD in Complex Needs?

Bob Buckley

Victoria has a Multiple and Complex Needs Initiative (MACNI). According to the website (see http://www.dhs.vic.gov.au/complexclients/index.htm) it

> … is an Initiative of the Department of Human Service (DHS) jointly funded with the Department of Justice (DoJ).
>
> MACNI is a time-limited specialist intervention for those 16 years and older who are identified as having multiple and complex needs including those with combinations of mental illness, substance abuse issues, intellectual impairment, acquired brain injury and forensic issues. Often these individuals pose a risk to themselves and to the community.
>
> MACNI targets 50 individuals per year.

The report shows 26.9% of the client group have mental disorders including Asperger's and autism (see http://www.dhs.vic.gov.au/complexclients/downloads/complex_clients_casestudies.pdf). There is substantial evidence that the much of the mental health sector in Australia is chronically incapable of recognising or responding to ASD in patients. So there is likely to be substantial under-diagnosis of ASD in this context.

The initial discussion of this initiative indicated Asperger's Disorder was associated with 1/3 of those involved. Yet for some reason the Autism Spectrum had been omitted from the list of “issues” in subsequent discussion. As can be seen above, the issues associated with this Initiative are …

> "combinations of mental illness, substance abuse issues, intellectual impairment, acquired brain injury and forensic issues."

Downloading all the documents referred to on the MACNI documents page (see http://www.dhs.vic.gov.au/complexclients/html/reports.htm), and searching for “autism” or “Aspergers” reveals that there is no reference to these terms after the initial documents (in 2002 and 2003).

The initial documentation says …

> ### Service gaps
>
> There are commonly held views that there are gaps in the service system in relation to this population. Families, carers and services highlighted the following gaps or omissions:
>
> • Lack of targeted responses to individuals with autism spectrum disorders, particularly Asperger’s Syndrome. These people are often identified as falling into service gaps, frequently deemed ineligible for both mental health and intellectual disability services.
>
> http://www.dhs.vic.gov.au/complexclients/downloads/complex_clients_phase1_rep.pdf page 6
>
> ### 2.8 Aspergers Syndrome
>
> The importance of Asperger’s Syndrome in any discussion of high and complex needs is highlighted by several authors.[70] In particular, a number of writers note challenges in providing appropriate responses to children and adolescents with Asperger’s Syndrome.[71] Accurate assessment is seen to be critical because it has direct implications for the types, and effectiveness of intervention. The Victorian Dual Disability Service notes[72] that the key challenge for specialist dual diagnosis services is ascertaining the best way to proceed in unusual cases which are not within the ‘normal’ range of a mental health caseload. ‘Patients with autistic features, such as Asperger’s syndrome, appear to pose particular problems as they are difficult to diagnose and can appear to have a psychotic illness and are often brought to the attention of mental health services who remain unsure whether this is a disorder that they can, or should, manage.’[73]
>
> Challenges also arise in the accurate assessment, and subsequent management of behaviours in other syndromes such as over eating in Prader-Willi syndrome, aggressive behaviour associated with a tuberous sclerosis and fragile X syndrome, and regressive behaviours which are not responsive to routine strategies, such as incontinence,

> intrusiveness, and unpredictable aggression in the context of a psychotic illness. Expertise in mental illness and intellectual disability is important to accurate diagnosis and development of appropriate strategies for care and treatment.
>
> http://www.dhs.vic.gov.au/complexclients/downloads/final_litrev8.pdf page 18

Despite this clear advice, reference to "autism" and "Asperger" have disappeared completely from subsequent project reports. Apparently, MACNI has not addressed the needs of people with ASD.

The latest report (see http://www.dhs.vic.gov.au/complexclients/downloads/mcan_regional_gateway_data_report_14-09-2007.pdf) shows disappointing outcomes. For example, of those referred to the project …

- 18% in stable accommodation … homeless category does not include 19% "other" and 17% "not identified" p14
- 412 cases >16 years of age, 359 need supervision (Figure 6 page 9). Most people (75%) have a "mental disorder" which can include Autism or Asperger's.
- Just 28% resolved and a monstrous 72% unresolved … comprising 9% not resolved and 63% "to be advised" … (Figure 9 page 11)

There are no discernible measures of outcomes; for example accommodation resolved, employment or day program, … not even case worker/manager or advocate in place, operational individual plan, completed regular health checks, adequate nutrition, operational support/social network …

Some might feel the signs are that Victoria's Multiple and Complex Needs Initiative is failing. It has

- growing numbers of repeat clients
- growing substance abuse
- growing number of "to be advised" and decreasing "resolved" cases (see Figure 9 - now 1 in 3.6 cases).

Could this be due in part to its failure to recognise the significance and impact of untreated autism spectrum disorders? Is this a sign that some people with ASD, who appear to be quite "high functioning", still need timely and appropriate services and supports? Does this show that mainstream mental health just doesn't get it?

Will the Victorian Government learn from this? Will anyone learn? Will Victoria's State Autism Plan suffer the same fate?

Victoria's intentions in developing and operating its Multiple and Complex Needs Initiative are entirely appropriate. The opportunities to learn from this project are a significant benefit.

ASD in the media

A-team hackers: teen 'leader' autistic

> … Walker, from Whitianga in New Zealand's North Island, has Asperger syndrome, which is often characterised by social isolation but great intelligence, the New Zealand Herald has reported. …
>
> http://www.smh.com.au/news/security/ateam-hackers-teen-leader-autistic/2007/12/03/1196530520791.html
>
> http://www.theage.com.au/news/security/ateam-hackers-teen-leader-autistic/2007/12/03/1196530520791.html

Fish oil may prevent schizophrenia

> … Omega-3 oils have been touted as a possible treatment for a range of conditions, including depression, bipolar disorder, rheumatism, heart disease and cancer.
>
> They have also been found to improve concentration and learning in children with ADHD and autism, and reduce aggression among prisoners. …

> http://www.theage.com.au/news/national/fish-oil-may-prevent-schizophrenia/2007/11/29/1196037018110.html
>
> http://www.smh.com.au/news/NATIONAL/Fish-oil-might-stop-schizophrenia-study/2007/11/29/1196036990650.html

Call for action on babies damaged by mothers drinking

> …. A hard-hitting campaign launched today will warn that one in 100 Australian newborns could be suffering irreversible brain damage caused by alcohol exposure in the womb.
>
> Sufferers can have birth defects, learning difficulties and complex behavioural issues. But only 2% of doctors feel confident in detecting the condition and many children are misdiagnosed with attention deficit disorders, hyperactivity and autism. …
>
> http://www.theage.com.au/news/national/call-for-action-on-babies-damaged-by-mothers-drinking/2007/12/02/1196530480989.html

An article in “Scotland on Sunday” (see http://scotlandonsunday.scotsman.com/index.cfm?id=1819462007) seems to be the source of this beat-up. It looks like the alleged journalist either misunderstood claims that some children with foetal alcohol spectrum disorders (FASD) are misdiagnosed with autism (that is, they do not have autism at all) or simply made up a link between alcohol and autism.

Hmmm. I looked in PUBMED for any sign of new research behind this story. Searching for “autism” and “FASD” found just one article …

> **Bishop S**, **Gahagan S**, **Lord C**.
>
> University of Michigan Autism and Communication Disorders Center, Ann Arbor 48109, USA. bishops@umich.edu
>
> BACKGROUND: Autism spectrum disorder (ASD) and fetal alcohol spectrum disorder (FASD) are both characterized by social difficulties, but overall clinical descriptions of the two disorders are different. METHOD: Twenty-nine children with autism and 33 children with pervasive developmental disorder-not otherwise specified (PDD-NOS) were compared to 29 children with FASD of equivalent age and full-scale IQ. To isolate social deficits that are most unique to ASD, all participants were administered the Autism Diagnostic Observation Schedule (ADOS). Parents of the children completed the Autism Diagnostic Interview-Revised (ADI-R). RESULTS: Difficulties in initiating social interaction, sharing affect, and using nonverbal communication were common in children with ASD but rare in children with FASD. Socially inappropriate behaviors and difficulty with peers were common in both groups. CONCLUSIONS: These findings suggest that whereas propensity for social interaction appears to be a differentiating factor between children with ASD and those with non-spectrum disorders, impaired quality of social interaction may be less diagnostically discriminative.
>
> PMID: 17995487 [PubMed - in process]

The story in The Age mentions autism in the context of misdiagnosis. It is rare for a doctor in Australia to diagnose autism. A4 would be very interested to know how many “doctors feel confident in detecting …” autism and related disorders.

Misdiagnosis of autism is a beat-up — no evidence is offered. The Government could easily test claims of autism misdiagnosis by reviewing a sample of ASD diagnoses for FASD. If significant misdiagnosis turns out to be the case, its up to the Health Department to highlight a need for care in differentiating ASD and FASD in diagnostic processes.

It would be great news to find that the “autism epidemic” is due to misdiagnosis and can be prevented through pregnant women drinking less or not at all.

Frankly, it is unbelievable. Let’s see the evidence.

Mother's flu could lead to mental illnesses

> … WOMEN who catch the flu during pregnancy are up to seven times more likely to have a child with schizophrenia - and scientists believe they have finally figured out why.
>
> A rogue protein, interleukin 6 - produced when a pregnant woman is fighting a viral infection - may help trigger mental illnesses such as autism and schizophrenia in the child, US neuroscientist Paul Patterson said yesterday. …

http://www.news.com.au/story/0,23599,22079407-2,00.html

Vietnam vets 'passing on mental problems'

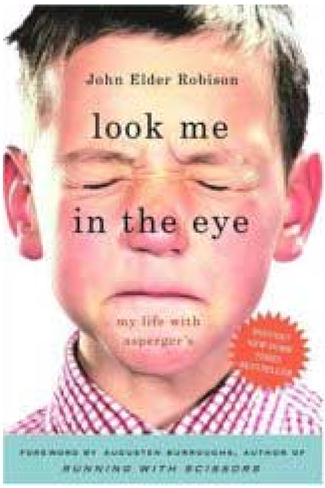
… Mr O'Brien, who is from the university's School of Social Change Research and is the son of a Vietnam veteran, is studying the phenomenon, which he says is widespread.

He said it was causing attention-deficit hyperactivity disorder (ADHD), autism, Asperger's syndrome and depressive and anxiety conditions in children and grandchildren. …

http://www.news.com.au/story/0,23599,21931712-1702,00.html?from=public_rss

Book Review

Look Me In The Eye - John Elder Robison



Publisher: Crown; 1 edition (September 25, 2007) **ISBN-10:** 0307395987

Look Me In The Eye is the moving, darkly funny story of growing up with Asperger's at a time when the diagnosis simply didn't exist. A born storyteller, Robison takes you inside the head of a boy whom teachers and other adults regarded as "defective,"...... He also provides a fascinating reverse angle on the younger brother he left at the mercy of their nutty parents—the boy who would later change his name to Augusten Burroughs and write the bestselling memoir Running with Scissors. Ultimately, this is the story of Robison's journey from his world into ours, and his new life as a husband, father, and successful small business owner—repairing his beloved high-end automobiles. It's a strange, sly, indelible account—sometimes alien, yet always deeply human.

WA Planning Office transfers crown land

4/12/07

Services to people with autism and their families will be expanded, following the State Government's transfer of Crown land to the Autism Association of Western Australia.

Located on Stubbs Terrace, Shenton Park, the 3,646sq.m site will be used by the Association for clinical and support services and has been provided at the nominal value of $100,000.

Planning and Infrastructure Minister Alannah MacTiernan said the land transfer would result in improved services to people with autism and their families.

"I am very pleased we have been able to make the land available for this purpose at greatly under the land's market value," Ms MacTiernan said.

"The Autism Association carries out a valuable role in the WA community and I'm delighted we are able to give back to this deserving cause."

Disability Services Minister Sheila McHale said autism spectrum disorders often presented a lifelong challenge for individuals and families and many children and adults required significant levels of support.

"We know the number of children diagnosed with autism has increased substantially over the past decade in WA, nationally and internationally," Ms McHale said.

“The association plans to address this increased demand through an expansion of services from early childhood through to its adult support programs.

“The Stubbs Terrace site will accommodate a new, purpose-built early intervention centre, family support facilities, clinical services and the association’s service management team.”

Ms McHale said the Carpenter Government had already increased funding for early intervention services for pre-school children, including children with autism and provided more than $6million in 2006-07 to the association for services.

“The Autism Association is a critical part of our support network and I am pleased this transfer provides it with surety and opportunities for growth to benefit people with autism and their families and carers,” she said.

WA Autism Association CEO, Joan McKenna-Kerr said the land transfer was the first phase of a three-year plan to increase the organisation’s capacity to meet the needs of a growing number of people with autism and to provide support to their families.

Mrs McKenna-Kerr said the association could now embark on the next major course of service development and expansion.

“We are delighted the State Government has recognised the importance of building our service capacity,” she said.

“We estimate that within three years, our early intervention services to newly diagnosed pre-school children with autism will increase from our current capacity of 155 children to about 200 children a year.

Our post school options program for school leavers will increase by at least 40 per cent.

“We also have plans for continued annual growth in clinical services, residential services, employment support programs and family support and we are now developing strategies to secure funding for this exciting project.”

Planning and Infrastructure Minister’s Office - 9213 6400
Disability Services Minister’s Office - 9213 6900

Members Letters

(Written by a mother to the Victorian Autism Plan)

To whom it may concern,
I am a mother of a boy aged 5 yrs who has High Functioning Autism and is about to embark on his journey through school. I am deeply anxious and scared of the upcoming transition and the effects it will have on my son and my family. Jack has been attending Windermere Biala in Cranbourne Vic for the past year as well as attending mainstream 4 yr old kinder where he received full funding for an aide for every hour that he attended. As we begin his school life we are faced with the daunting and costly task of preparing a profile of him with reports from Psychologists, Speech therapists, teachers, Paediatricians and Audiologists, in order to receive some sort of funding for school. We are still waiting for the outcome even though orientation has begun!

I enquired with the staff at Biala with regard to the services available for families and children when they begin school. I wanted to know about getting help with the transition, tips and ideas on preparing not only my child but also the school for when he starts. I was shocked to find there is nothing. If my child doesn't receive any sort of funding, which is very likely according to what I have heard, I feel we are being hung out to dry.

My child has been eligible to attend an integrated care kinder, he has had full funding for an aide for every hour that he attends a mainstream kinder, has reports from his Psychologist, Speech therapist, Paediatrician etc; this shows the government sectors recognise there is a problem, however, to receive funding for school I have to prove my sons condition all over again; more than likely we will then be told no he doesn't qualify for additional help. He has a health care card for disability, I am able to receive a carer's pension of $100 a fortnight, and these merely have to be updated each year by a stamp from our local G.P !

To the decision makers who have the task of allocating budgets; you need to be able to understand the effect this has on parents of children with an autism spectrum disorder. I would like you to know how heart breaking it is to hear our son crying in his sleep, reliving the nightmare of social overload that he has endured over the course of his day while having to try to socialise and function in a social environment. He does not know the skills or have the ability to block out fragments of his day that are truly painful for him. The fact is, we are about to send him to a place that has many children (something that can set off an anxiety attack) a place where expectations are high, and a place where he can get bullied and labelled for something he has no control over. He does not have the skills to be able to cope and he will need help and support.

I, as his mother, know him and I am able to understand his behaviours and prepare him for transitions in his day, but I am about to let him go off into the wide world by himself with nobody there watching his back. It's not enough that he may not cope, it's the fact that I have to come to the realisation that my child may suffer high levels of anxiety and he may need to be medicated because he won't be able to deal with the social side of school. He was born with ASD and social situations are like a torture to him. You need to understand what its like for a mother and a father to hear their child explain to them that they were crying at school orientation (having a melt down) because "my head hurt" when asked why the response was "there are too many kids and I got a headache". This is from a child who is two standard deviations below average for receptive and expressive language. This whole situation was only from a one and a half hour visit. It makes us cry and reassess whether we need to send him to school; are we doing the right thing? This is something parents of any child would ponder regardless of whether they have special needs.

We believe every child who receives services such as those at Biala should be funded to go off and start their school life and be followed up in their first one or two years of school. Funding should be allocated for those trained professionals who are familiar to the children to be part of the school program, offering help and assistance to the school, staff and the other children who attend and, most importantly, to the child with ASD and their families. Funding is also needed for children who fall into the ASD spectrum and are on the high end of the spectrum. These children may be above the line for services at special schools, and they need to be able to have a set minimum number of hours available for an aide at school.

The cost of having a child with ASD is hugely expensive with psychologists, private speech therapy etc. Simply for my husband and I to get Jack's report completed and lodged to seek funding for school has come at a personal cost of $1600 most of which is non claimable. This comprised of $800 for a psychologists bill (an updated report that had not change since diagnosis) $360 in speech therapy costs (to sit tests so he can be marked and receive a overall score) plus an additional $110 for the report to be written, $100 odd dollars for an updated audiology test to prove that he hasn't really been deaf for all this time, $160 updated paediatrician report (that concluded with the diagnosis, said that the mother is doing everything she can and that the child suffers anxiety) $40 for a report from his local GP confirming all other reports, and many reports from teachers and carers. All this is a huge financial burden but it also does not cover the time and emotional burden of putting together such an extensive package. We have to tell our story over and over again. After all this we are still basically waiting until next year to be told yes or no to funding. Hopefully this will be BEFORE he starts school. Its as if we are being told "you and your child will just have to suffer because all these expensive and conclusive reports isn't enough recognition, because there is basically not enough money to go round, good luck and you can protest the decision". Parents then wonder where this leaves them and their children.

This process is exhausting; exhausting on the families, other siblings and the child with ASD.

I hope this helps in your decisions on what to do for children with ASD and how extra funding will enable these gorgeous, special often misunderstood children manage through their years of school, allowing parents to breathe a bit easier.

Yours faithfully
Shannon Cassidy,
Mother of a very beautiful, intelligent, witty, charismatic 5yr old with ASD, Jack.

A Christmas Poem:

copyright Donna Williams 2007

Joey ate the cup cakes and is bouncing off the wall
Jenny stripped her clothes off and has run off down the hall
Jimmy liked the pieces of his now demolished toy
Jane's exploring mania as self manufactured joy.

Josh enjoyed the ribbon and has cast aside the gift
Jasper's glued upon the sofa and may never shift
Johann's licking batteries which give a funny jolt
A guest has left the door unlocked, and Jack's about to bolt.

Jeremy is hanging out with his reflection in the mirror
Jasmine's now won't touch the food as beetroot's in the dinner
Johnny ate the recipe and now you have to guess
Jacob's wearing decorations, so now the tree has less.

Jeffrey's left a smelly gift for all upon the wall
Jordan's washed your cashmere sweater, making it 'size small'
Joanie's cleaned the rugs of lint, she's chewing it right now
Jet would say he loved you if he could only work out how.

Merry Christmas all

Warmly,
from Donna Williams
http://www.donnawilliams.net

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.

Anti-spam: change -at- to @ in email addresses.

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