A4 Update
Autism Aspergers Advocacy Australia

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Special needs student funding attacked

JOANNA VAUGHAN, POLITICAL REPORTER

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TEACHERS find it impossible to properly educate students with special needs because they lack staff and resources and are not properly trained, the teachers union says.

Hundreds of angry parents today joined the Australian Education Union on the steps of Parliament House, urging the State Government to provide more funding for schools to support special needs children.

They say facilities in South Australia are far inferior to those interstate and they often have no choice but to either keep their children at home or send them to private schools.

Father of five children, including two with autism, Garry Connor, said he was forced to use private education because the public system did not provide adequate support.

"We are close to the poverty line, but we have to send our kids to private school, because the public system just can't support our children," he said.

"The Government says how they are spending millions over the last seven years they have been in power, but our children still struggle so I don't know where these millions are going to

"They say how they have spent more money than any other state does, but we are still the backwater in autism. The resources interstate are just so much better. But I am a South Australian and I want to live in South Australia.

"There are 2500 empty seats in schools every day where, for a number of different reasons whether it be behaviour problems, or violent problems or parents have just have had enough and they can't take any more, they take their children out of school where they do home schooling because teachers just can't support them."

The AEU is demanding one teacher for every four special needs student, an SSO for every special class in mainstream and special schools, specialised training for staff who work with such children and more resources for schools.

The current ratio is one teacher per eight special needs students.

AEU SA branch President Correna Haythorpe said there had been an increase in 75 per cent in special needs schools since 2000 and 40 per cent of these are in mainstream schools.

"Current resources provided by the State Government in our schools and special schools just aren't adequate," she said.

"In mainstream schools in particular, educators are finding it increasingly difficulty to meet the needs of all students. The task is made almost impossible with the increase of students with special needs such as autism who have a rightful place in mainstream classes but require intensive early intervention and ongoing support."

Ms Haythorpe said parents had recommended the State Government also provide funding for a specialised special needs school.

Greens MLC Mark Parnell, Independent MLC David Winderlich and Liberal MPs David Pisoni and Stephen Wade also attended the rally.

Department of Education and Children's Services chief executive Chris Robinson said the education budget was at record high levels and since 2002, the State Government has increased funding to all students with special needs by $120 million.

"The education department provides more than $200 million annually overall to support students with disabilities,'' he said.

"Since 2002 the number of students with disabilities in mainstream classes has increased by about 22 per cent.

"DECS provides a range of support options to cater for students with disabilities including students with Autistic Disorder and Aspergers Disorder.

"The range of support options include mainstream schools with support, special schools, disability units and special classes as the needs of children with autism vary considerably.

"Students with disabilities, including those with Autistic Disorder and Aspergers Disorder, are supported with the help of specially trained staff, School Services Officers (SSOs) and special equipment and resources.

"Each educational region has specialist staff such as psychologists, speech pathologists and disability coordinators who are able to offer professional advice and training and development to support to teachers and families of students with disabilities.''

From http://www.news.com.au/adelaidenow/story/0,22606,26182442-2682,00.html?from=public_rss

Also http://www.abc.net.au/news/stories/2009/05/12/2568485.htm?site=adelaide

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Convenor's message

Dear A4 member,

The previous A4 Update has a short item about a Rotary Mental Health research grant. I congratulate Peter Hill and the Dapto Rotary Club for their achievement. ASD research is an enduring passion for Peter, one of A4's most active committee members.

A4 is not set up for fund-raising or to manage a research grant process. If A4 members want to contribute some part of their fund-raising efforts to a worthwhile ASD-related project, I encourage you to join Peter in this effort.

Australia needs much more ASD research. Rotary's Mental Health Research project already exists and the Rotary organisation contributes dollar for dollar so, thanks to Rotary clubs around the country, every $1 you raise or contribute puts $2 into ASD research.

I encourage Peter, Dapto Rotary and Rotary's Mental Health Research to continue collecting funds for autism/ASD research in Australia.

At APAC '09, Bill Shorten announced that the federal government is interested in establishing a National ASD Register. The federal government contracted to state autism associations to develop a proposal. The latest Australian Advisory Board on Autism Spectrum Disorders (AABASD … see http://www.autismaus.com.au) Communiqué says:

> **ASD Register Proposal:** The state and territory autism organisations had pooled their funding in order that the Advisory Board develop a single comprehensive proposal to FaHCSIA for a national all ages ASD Register.

See http://autismaus.com.au/uploads/pdfs/CommuniqueAABAugust2009.pdf

Federal government is considering their National Autism Register proposal. The signs are that this will progress relatively quickly.

The Victorian Government may be in for a surprise, though, when it discovers (and if it acknowledges) the number of Victorian children with ASD. Their Department of Education and Early Childhood Development has an autism webpage (see http://www.education.vic.gov.au/ocecd/earlychildhood/library/publications/ecis/autism.html) that says:

> **Incidence**
>
> Using the DSM-1V incidence, autism occurs in 2.5 in every 10,000 children.
>
> Autism spectrum disorders have more recently been suggested to be 10 in every 10,000. Boys are three times more likely to be affected.

This is just rubbish – wrong in so many ways. Even quoting the very outdated prevalence (not incidence) estimate for Autistic Disorder (not autism) in the DSM-IV-TR (published in 2000), the Department could at least quote the source correctly ("5 cases per 10,000 individuals …", not 2.5). More recently, ASD is at least 60 per 10,000 and most recently over 100 per 10,000. Boys are 4 times (not three times) more likely to be affected than girls. Of course, better information is available now: they should just refer people to some of the new federally funded websites.

I hope the Victorian Government does not plan and provide education and early childhood services for people with ASD on the basis that 2.5 per 10,000 Victorians have Autistic Disorder and 10 per 10,000 have ASD.

The evidence in both Australia and the USA that the number of children diagnosed with ASD now exceeds 1% may be a psychological tipping point for governments, communities and employers. There are signs that the US Government has suddenly become more interested in finding causes and strategies for ASD. Perhaps Australian ASD prevalence reaching 1% of children will be a catalyst for the Commonwealth Government to hold an Inquiry to consider community concerns such as access to treatment, education outcomes, appropriate accommodation for adults with ASD and the level of research that is appropriate – to name a few.

Perhaps this will be a wake-up call that leads to some serious revision of employment policy and practice. People on the autism spectrum should be seen as part of the workforce productivity solution rather than a problem.

People interested in employment for people with ASD may be interested in the UK National Autistic Society's *Don't write me off* campaign (see http://www.dontwritemeoff.org.uk/). And there is an article in the UK Guardian (see http://www.guardian.co.uk/money/2009/oct/17/employing-adults-with-autism).

If you did not see Danish businessman, Thorkil Sonne, (who created a business called Specialisterne that is focussed on employing people with Asperger's Disorder and ASD) at APAC '09 then you can hear him on the ABC's Life Matters program at http://www.abc.net.au/rn/lifematters/stories/2009/2670002.htm or read about his efforts at http://en.wikipedia.org/wiki/Specialisterne and http://www.specialisterne.com/. Or watch Thorkil's presentation on the APAC '09 DVDs.

Thorkil Sonne has a clear message for HR sections in major organisations. Perhaps you can pass this information on to people in HR departments where you work.

One of my favourite websites is TED.com. Each week TED adds a video of an impressive presentation on some subject.

Recently, Rebecca Saxe gave a TED talk about brain function and theory of mind – see http://www.ted.com/talks/rebecca_saxe_how_brains_make_moral_judgments.html. I think this talk could help anyone involved with motivation and behaviour of children.

Here are some other TED talks that I found interesting:

- http://www.ted.com/talks/lang/eng/michael_merzenich_on_the_elastic_brain.html
- http://www.ted.com/talks/lang/eng/james_watson_on_how_he_discovered_dna.html.
- http://www.ted.com/talks/peter_donnelly_shows_how_stats_fool_juries.html
- http://www.ted.com/talks/arthur_benjamin_does_mathemagic.html
- http://www.ted.com/talks/hans_rosling_shows_the_best_stats_you_ve_ever_seen.html

Recent reports show the AMA has joined the call for a national disability insurance scheme (see http://news.theage.com.au/breaking-news-national/disability-insurance-scheme-needed-ama-20091007-gmzv.html).

How do you feel? Should A4 also support the proposal for a national disability insurance scheme (see their website at http://www.ndis.org.au/)? If so, what do you expect such a scheme would provide for people with ASD?

Regards
Bob Buckley
October 2009

The Shorten Curlies: volume 2

This is A4's second group of challenging ASD-related issues for the Australian Government. The previous A4 Update explained the origin of the column and introduced an initial four "curly" issues relating to ASD in Australia.

As yet we do not have a response from the Government to the initial set of "curlies" … nor an acknowledgement that they received them.

SC#5. **Education outcomes for students with ASD**. It is clear from Table 2 in the AABASD (2007) report, *The Prevalence of Autism in Australia: Can it be established from existing data?* (see http://autismaus.com.au/index.php?page=research) that education departments around Australia have relatively poor data relating to students with ASD. The ASD rates reported from state education departments vary rather erratically from more credible sources (especially, Centrelink). Apparently, state education departments do not know what outcomes students with ASD achieve or how effective education services are for students with ASD. From this one can infer that state education departments do not know what resources they need to provide so they ensure equitable outcomes for students with ASD.

Indications are that a high proportion of people with ASD in their post-school years receive a Disability Support Pension. This suggests that the available

education does not prepare people with ASD effectively for employment and/or post-education employment services are ineffective for people with ASD.
Education Departments should monitor and report education outcomes for people with ASD.
It appears that an increasing number of students with ASD get tertiary qualifications but are still unable to get jobs. While some do get jobs, their jobs do not make effective use of their training and skills.

SC#6. **Schools excluding students with ASD**. Education systems/bureaucrats in Australia (and elsewhere in the world) decided that students with disabilities should be "integrated" or "included" in mainstream education settings. Rather than offer segregated education, funding for educating students with a disability would be used to provide the required service for the student in a mainstream setting.

Many people regard this inclusion model as desirable and appropriate.

While this model often works well for students with a disability, the unfortunate reality for many students with ASD is that placements in mainstream schools have not worked out as intended or desired. Governments have not provided sufficient funding and resources, nor ensured students with ASD are prepared adequately, for effective education in mainstream schools. For students with ASD, Governments use inclusive education as a cheap and often ineffective option for students with ASD.

For example, the ACT Government sought recently to allow schools to exclude students for 10 days (without telling the Education Department … up from 5 days. The ACT Opposition wants schools to be able to exclude students for 20 days. The ACT Government does not show how this will improve education outcomes for children with ASD. The experience of parents is that an excluded student's behaviour does not improve; rather it deteriorates as the student learns that bad behaviour helps them avoid the school setting that they hate. The student spends an increasing amount of time out of school. A parent may need to stop working so the family's economic situation deteriorates. Stress and mental health issues in the family escalate.

Many students with ASD do not get the support they need in mainstream schools. Consequently, students with ASD are excluded too often from the school where they are enrolled. The issue is raised in several recent media reports.

- http://www.theaustralian.news.com.au/story/0,,25982712-13881,00.html
- http://www.abc.net.au/news/stories/2009/08/26/2667147.htm
- http://www.abc.net.au/worldtoday/content/2009/s2645607.htm

A few families complain formally but most do not. The Australian Human Rights Commission reports some conciliations arising from these complaints result in increased resource allocations (see http://www.hreoc.gov.au/disability_rights/decisions/conciliation/education_conciliation.html). Those students whose parents do not complain miss out on an effective education. In Australia, students do not have a right to an education, or even a right to attend school.

SC#7. **ASD research**. The cost of ASD to the Australian community is large. With the apparent increase in the number of people affected, the apparent cost is also growing substantially. Despite the considerable cost of ASD to the community, Australia spends very little on ASD research.

Recently, the US Government recognised ASD prevalence now exceeds 1% of children and this realisation apparently provoked the US Government to increase its ASD research.

As yet, the Australian Government has not explained why it is not funding ASD research at an appropriate level. More recently, it put $190 million into its Helping Children with Autism package over a 5 year period yet it did not increase ASD research.

The latest Australian data suggests more than 1% of Australian school-age children are now diagnosed with ASD. ASD prevalence has more than doubled every 5 years since the 1980s. Surely, this growth in a severe disorder deserves serious investigation.

SC#8. **Workforce development**. Australia needs an increasing number of clinicians to deliver best practice intervention, treatment, rehabilitation and support for people with ASD. For example, students with ASD need clinical support in school to address their behaviour challenges rather than allowing schools to exclude students with ASD (see SC#6 above).

Since the 1990s, Australia has not had the workforce capacity needed to deliver the level of service required. The number of Australian children diagnosed with an ASD has more than doubled each 5 years since then and service capacity is hugely behind demand.

A particular concern is that tertiary education institutions need to significantly improve their training quality and increase the quantity of allied health professionals needed to provide ASD-specific clinical services for people with ASD.

SC#9. **ASD Peak Body**. According to the FaHCSIA website:

In Australia there are several national disability peak organisations that contribute to government policies about disability issues affecting Australian families and communities, to carry information between government and the community on social policy issues and to represent constituent views.

See http://www.facsia.gov.au/sa/disability/progserv/providers/AustralianDisabilityEnterprises/Pages/DisabilityPeakBodies.aspx

None of the groups listed represents people with autism spectrum disorders. The website says the Department funds most of these organisations “to be the peak body …” for specific disability groups. The webpage even lists two different deafness groups.

People with ASD are a distinct disability group. We hope that Governments recognise that now that over 1% of Australian children are now diagnosed with ASD, ASD is by definition at least a severe and usually life-long disorder, and people with ASD have ASD-specific needs distinct from other types of disability (people with ASD may also need some generic (specialist?) disability services).

People with ASD need ASD-specific representation: it would help if the Government were to contribute to funding such representation as it does with so many other disability peak bodies.

Status of Shorten Curlies from previous editions of A4 Update

Shorten Curlies from Volume 7 No. 5

SC#1 **ASD and accessing Commonwealth State/Territory Disability Agreement (CSTDA)-funded services:** No change.

SC#2 **PDD-NOS and Carer's Allowance**: No change.

SC#3 **Disability discrimination in Australian Law**: No change.

SC#4 **Nature and cost of Best Practice early intervention for ASD**: No change.

A4 members are encouraged to use this forum to raise further challenges for the federal government. Please send your suggestions for this column to editor@a4.org.au.

No *Fair Go* for Children with Autism

Australian children with autism want a *fair go*. The FAQ[1] on the Human Rights Consultation website says:

> "Australia has agreed to uphold the human rights standards set out in a number of international treaties and declarations, …
>
> "This means that Australia is obliged to give effect to the human rights obligations contained in these documents."

Among the rights described in the "international treaties and declarations" are children's right to medical care, treatment, rehabilitation, education, etc. Children with autism spectrum disorders (ASD) need these rights recognised and respected if they are to have any hope of equitable outcomes and general participation in our community.

These rights are not respected in Australia. For example, data show that fewer than half the people with ASD received any service through the Commonwealth State and Territory Disability Agreement (CSTDA); and there is no evidence that those who received any service got a service that met their needs. Data also shows people with ASD have especially high rates of severe or profound disability so most of them have high services needs.

While Australian Governments have signed international treaty documents, apparently obliging governments to enact and enforce them, many of our politicians and legal officials strongly oppose giving Australian citizens human rights.

Former Labor Premier, Bob Carr, is critical of human rights. He says the law doesn't work and Conservatives would add property rights (See http://www.theaustralian.news.com.au/story/0,25197,25448539-5013871,00.html). He is worried about letting unelected judges decide such issues (though Australia's ultimate leader(s) are not elected either).

In relation to children's right to education, Bob Carr wrote

> "…Before long the exercise of classroom discipline by teachers or principals will run the risk of litigation. This will then force changes to school practice in anticipation of which way a court may jump".

Recently, "The National Human Rights Consultation Committee handed its report to the Attorney-General, the Hon Robert McClelland MP, on 30 September 2009"[2]. The

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[1] see http://www.humanrightsconsultation.gov.au/www/nhrcc/nhrcc.nsf/Page/FrequentlyAskedQuestions_FrequentlyAskedQuestions

primary recommendation, rather than the provision of any actual rights, is "that education be the highest priority for improving and promoting human rights in Australia". It recommends "a federal Human Rights Act" based on "the 'dialogue' model" and is limited to "federal public authorities". Presumably the states can avoid human rights as they wish. Remarkably, it seems to recommend that priority be given to ensuring complaints about "the right to … physical and mental health" and "the right to education" "not be justiciable" (*justiciable* means able to be *decided by a court*[3]).

Australian politicians are mostly united in opposition to betterment of human rights for Australians yet they readily criticise other countries on their human rights performance.

> "Attorney-General Robert McClelland seemed terrified of giving the slightest endorsement to the report when it was released this week."[4].
>
> "Opposition legal affairs spokesman George Brandis said the Brennan report would 'bring a culture of litigation to the heart of the public service for the first time'"[5].
>
> "FORMER High Court judge Ian Callinan has warned that the introduction of a charter of rights would ultimately restrict access to the High Court and grant undue power to activist judges"[6].

Currently, our courts and tribunals say that, while many children access health treatment, governments can refuse to provide any treatment whatsoever for a child's ASD. The legal system does not regard governments who are responsible for health services, yet refuse to provide treatment for ASD, as discriminating against children with ASD. The legal system says if refusing to offer or provide essential health care were discrimination, such discrimination would be lawful anyway.

In Australia, it is not a human rights problem that a tribunal takes more than 6 years to reach such a decision, thereby denying any prospect of a timely remedy. Clearly an Australian child with ASD does not have a basic human right, the right to a competent (timely) legal system.

Australia's High Court says schools can exclude a child with a potential for disability-related behaviour. If a school is not comfortable with a student with a disability such as ASD, the school can just exclude the student. And it may not just be schools who can exclude people with ASD or any unwanted disability-related behaviour. Commentary in The Sydney Law Review 2004, Vol. 26, No. 4 on *Purvis* in the High Court (see http://www.law.usyd.edu.au/slr/docs_pdfs/editions/slr_v26_n4.pdf) says:

> "However, even if it is possible to narrowly confine the principle to disturbed behaviour, it still implies an erosion of the protection of people with such disabilities and ignores the fundamental difference between situations where the behaviour is uncontrolled and where it is an act of free will. If the principle is to be regarded as of general application, it sets an extremely dangerous precedent and would seriously undermine the purposes of antidiscrimination law on a broad scale." P191

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[2] see http://www.humanrightsconsultation.gov.au/www/nhrcc/nhrcc.nsf/Page/Report

[3] see http://legal-dictionary.thefreedictionary.com/Justiciable

[4] see http://www.theaustralian.news.com.au/story/0,25197,26188812-7583,00.html

[5] see http://www.theaustralian.news.com.au/story/0,24897,26189707-601,00.html

[6] see http://www.theaustralian.news.com.au/business/story/0,28124,26196659-17044,00.html

Rather than protect people with a disability, Australia's legal systems protect and possibly promote discrimination against people with a disability. Apparently politicians want to keep it this way.

Australian politicians are not talking about any alternative to human rights that ensures children with ASD can access the medical care, treatment, rehabilitation, education, etc. that they need. The political challenge of human rights for children with ASD was raised in the previous A4 Update as *Shorten Curly number 3*. Without a real right to essential services for their ASD, there is little prospect that Australia will give its citizens with ASD a *fair go*.

Bob Buckley 14/10/2009

Updating autism/ASD prevalence estimates in the USA

A recent article in *Pediatrics* (a US Journal) describes a finding that 1 in 91 US children had ASD from data in a 2007 survey (see http://a4.org.au/a4/node/172 or http://pediatrics.aappublications.org/cgi/content/abstract/peds.2009-1522v1). This is up from the previous average 1 in 150 that the US government Centre for Disease Control (CDC) reported based on its 2002 data for 8 year old children.

On its website (see http://www.cdc.gov/ncbddd/autism/index.html) the CDC has recognised this report and now says:

> CDC joins with HRSA in recognizing that ASDs are conditions of urgent public health concern and these data affirm that a concerted and substantial national response is warranted. We will continue to research potential risk factors associated with ASDs and will continue our work in surveillance so that we can understand trends in ASD rates over time. We hope that these new data might raise awareness about ASDs to help improve early identification and intervention and to provide information for policy and service planning, which will ultimately help to meet the growing needs of individuals, families, and communities affected by ASDs
>
> For more information on the coordination of public and private research on autism: Interagency Autism Coordinating Committee (IACC)

Other links to media cover include:

- http://www.autismspeaks.org/press/autism_nchs_prevalence_study_1_in_91.php
- http://psychcentral.com/news/2009/10/05/autism-now-in-1-in-91-children/8778.html
- http://www.reuters.com/article/pressRelease/idUS193657+06-Oct-2009+BW20091006
- http://www.google.com/hostednews/ap/article/ALeqM5gHxEgjNANQnxUq7-q4DYJIOo-R-wD9B4N4880

Government announcement

Expanded autism services begin today

19 October 2009

Joint Release from The Honourable Jenny Macklin, MP, Minister for Families, Housing, Community Services and Indigenous Affairs, and The Honourable Bill Shorten, MP, Parliamentary Secretary for Disabilities and Children's Services

Around 1400 children with Autism Spectrum Disorders will have easier access to early intervention services from today, following changes to the Rudd Government's Helping Children with Autism package.

The changes will increase the number of service providers, and allow families more time to use the $12,000 in early intervention funding available under this package.

This funding gives children with Autism Spectrum Disorders the chance to benefit from a range of early interventions, including one-on-one intensive activities and tailored group and individual programs.

Under the changes, families with children approved for early intervention funding will also be able to access early intervention funds until the child's seventh birthday.

This has been increased from six years, and will give families an extra year to access autism services.

Families will still need to have their child diagnosed with autism before their sixth birthday and see an autism advisor to receive early intervention funding.

Due to significant demand, some families had been placed on waiting lists and have not been able to use their full funding package before their child's sixth birthday.

Parents who have lost access to their approved early intervention funding because their child turned six, will now be given an additional 12 months to use the funding.

The new arrangements will also allow additional speech pathologists, occupational therapists and psychologists to participate in the autism program, subject to quality requirements.

Under the previous requirements, individual professionals could only be approved if they formed or joined consortia and operated as part of a team. Now these providers can join the program individually, increasing the number of service providers families can access across Australia.

While estimates on the prevalence of Autism Spectrum Disorders vary, it is widely accepted that as many as one in 160 children are affected.

To give these children the best chance in life we must make sure they get the early intervention support that is so important for their development.

For children with Autism Spectrum Disorders early intervention can make a huge difference to their quality of life and their ability to participate in the school system.

Since October 2008, more than 4100 children have accessed services under the $190 million Helping Children with Autism package, the first national initiative to help families deal with this challenging disorder.

From http://www.billshorten.com.au/press/index.cfm?Fuseaction=pressreleases_full&ID=2055

ASD in the news

Lessons from the death of a little girl

KATHRYN WICKS, The Sydney Morning Herald

7 October 2009

In sentencing the mother of Ebony - the seven-year-old girl from Hawks Nest who died of starvation - to life and her father to 12 years, Justice Robert Hulme of the NSW Supreme Court got one thing right. Their crime was reprehensible. No lesser sentence would have done. Nothing excuses her parents' inaction.

But it was also reported that although Ebony, who was autistic, had seen medical specialists about her disability, her parents had failed to follow through on therapies to address her speech and developmental deficiencies.

How could they? It seems apparent her parents did not have the financial means, and lacked the parental instinct and determination, to do the best for their child. Therapies for speech and developmental delays are of no use until an autistic child has been taught to behave appropriately and listen effectively.

In 2002 Ebony would have been two years old. Signs of her autism would have been visible: speech delay; failure to interact with others; failure to look anyone in the eye; uncontrollable behaviour.

Some baby nurses, GPs and pediatricians still wave away children with these signs and tell parents to come back in a year. Many mistake a lack of response for deafness, shifting the burden of telling parents their child is probably autistic on to audiologists.

But in 2002, when it could have made all the difference in the world to Ebony, there was no funding for behavioural therapy for children with autism. If waiting lists were as long as they are now it would have been 18 months before she might have seen a departmental speech therapist. And still she would not have been able to respond.

Somewhere between then and her death in 2007 Ebony's family gave up. Some parents do. While the strain from the cost and time of running a therapy program is just too much, many continue to take proper care of their children. Others, like Ebony's parents and Xuan Peng, a Canadian mother who drowned her four-year-old autistic daughter Scarlett in 2004, do not cope at all.

Shortly before Ebony's death the Howard government announced its Helping Children with Autism program. The new Labor Government picked it up and last October families with autistic children finally got some help: a child aged up to six now has access to $12,000 of therapy over two years. Except guidelines accepted by the Government say 2000 hours of therapy is the minimum needed, and that costs about $80,000.

Parents can get six hours of counselling a year. There are other, small amounts for speech therapy and the like. But information for parents is scattered across myriad websites, and exhausted parents have to jump through endless hoops to get their child's funding.

While it is not perfect, it is much better than when Ebony could, and should, have had access to intensive early intervention.

Yet effective therapy remains out of reach of most parents faced with this diagnosis. For others it means working unimaginable hours to pay for it. Others again will empty their savings accounts, withdraw superannuation, redraw their mortgage; borrow; or undertake training to turn themselves into therapists to reduce the cost. Or all of the above.

My son is autistic. I hear his swimming teacher say: ''He's better behaved than a lot of other kids.''

I hear his preschool teacher say: ''He's just one of the crowd.'' I hear him sing the alphabet and count to 20, like every other four-year-old (just don't ask him to draw a cloud).

And when I hear that, I know it has been worth every minute, and every cent. It is not a bad outcome for a child who, when aged two, could not, or would not, say ''Mum'', would not look anyone in the eye and was oblivious to those around him.

Autism Awareness says there is no cure, but there is hope.

It is time for the Federal Government to offer that hope to parents by funding fully the cost of effective treatment. Is $80,000 too much for the taxpayer to bear? Not when a 1998 US study, published in Behavioral Interventions, found the estimated saving to the education system alone of early intensive behavioural intervention to be worth more than $274,000 a child.

So means test funding; use a sliding scale; make insurance companies pay. Anything. But don't let Ebony's death be in vain.

Kathryn Wicks is a Herald journalist.

From http://www.smh.com.au/opinion/society-and-culture/lessons-from-the-death-of-a-little-girl-20091006-gl90.html#comments

Big-hearted tradies build centre for kids

Nick Dalton, The Cairns Post

14 October 2009

CAIRNS' building industry has thrown its support behind a $300,000 autism learning centre, committing $250,000 in materials and labour, despite the tough economic times.

But the campaign is $50,000 short and needs the public's help to complete new classrooms at the city's only autism school, at Edmonton.

More than 100 businesses, contractors and suppliers have supported the Cairns Helps Kids with Autism Campaign being launched today.

The school, in the former Hambledon State Pre-School in Marr St, has 32 children but with the new classrooms, two new offices and amenities it will be able to double its capacity.

Spearheading the project is builder Karl Maxa and his wife, Felicity, of Maxa Constructions, whose four-year-old son, Ben, was diagnosed with autism two years ago.

Mr Maxa said he had been overwhelmed by the support he had received from the industry since starting the campaign in September.

"I'm astounded. I am amazed at the generosity of the contractors and suppliers and how willing they are to donate their time and services to a good cause," he said.

"Their response has been, let's do it for the kids'."

Mr Maxa said he and his wife felt they had to do more for other families and children with autism after seeing first hand the positive effect early intervention services had on Ben.

Autism Queensland offers the only autism-specific intervention service in Cairns, including early intervention, outreach, education and therapy.

AQ provides a range of services to 32 children with autism under school age across the Far North.

Team leader Paula Burnett said there was a waiting list of 11 and 14 expressions of interest by parents wanting to send their children to the centre, which has been operating in Cairns for two years, the last year at Edmonton.

Mr Maxa said work on the new building would start on November 1 with the aim of finishing by Christmas for the start of the new school year.

He said teams of tradesmen would work on site Monday to Saturday.

Donations to the Cairns Helps Kids with Autism Campaign can made on www.autismqld.com.au through the Cairns Helps Kids with Autism Campaign link or post to Autism Queensland at PO Box 354, Sunnybank, Qld 4109. For further info, contact Karl Maxa on 0417 479 747, Felicity Maxa on 0408 603 085 or fundraising manager Paula Davidson on 3273 0000.

From http://www.cairns.com.au/article/2009/10/14/69831_local-news.html

Autism help not easy

6 October 2009, The Fraser Coast Chronicle

WHEN Susan Abel picked up the phone to inquire about how to get her hands on new government funding for autism services, she was surprised to find she was on her own - so to speak.

Susan, whose four-year-old son Sean has autism, was the only person from the Fraser Coast region to have registered her interest in the groundbreaking $12,000 funding announced last November.

Almost 12 months later and the Hervey Bay mum wants parents in the same situation to know what's out there.

An autism services information night to be held next Wednesday night in Hervey Bay will make parents of children with autism aware of what the Department of Communities has to offer.

Susan got her first hint of the possibilities when Kate McCarthy from Fraser Coast OT for Kids presented her with a brochure.

“I spent lots of hours on the internet. I had the luxury of having the time to do it. Some people just don't have that time,” Ms Abel said.

“Unless you're in the loop, you're never going to find out and you end up being missed out.

“It has made an extraordinarily positive difference to our lives. Hopefully others can have the same experience.”

She is hopeful that next week's information night will enable parents who have previously struggled to realise what is available, including up to $12,000 in grants for an early intervention program through the government.

[…]

For the full article see *http://www.frasercoastchronicle.com.au/story/2009/10/06/getting-message-out-about-help-for-autism/*

New autism centre for Burnie

15 October 2009

Parents of children with autism have welcomed the announcement of an early intervention service for Burnie.

The $5 million autism centre was announced in a previous Federal Budget but today the Community Services Minister Jenny Macklin announced Burnie as its location.

"We know that there is a very substantial need in the community," she said.

Six specialist staff will be employed help the children improve their social, cognitive and motor skills.

Andrew Barry has two autistic children and says such a service would have been an enormous help to him and his wife.

"We had to search far and wide for professional services, from both Melbourne and Sydney," he said.

The centre is expected to be finished mid next year.

From http://www.abc.net.au/news/stories/2009/10/14/2714394.htm

Also see http://www.alp.org.au/media/1009/msdcsecefcs140.php

Early intervention in autism

15 October 2009

by Jane McCredie, The Pulse, Australian Broadcasting Corporation

New diagnostic techniques and early intervention programs are improving the prospects for children with autism.

It may be too early to label a one-year-old boy who doesn't point or respond to his name as "autistic", says psychologist Robyn Young, but it is definitely not too early to intervene with targeted programs that could help to prevent him from developing the condition later on.

Young and fellow researchers at Flinders University in South Australia are part of a global push to identify children at risk of autism spectrum disorders (ASDs) at a younger age. Experts now generally agree that it is better to intervene before the behaviours associated with the condition have a chance to become entrenched.

"We have found that kids that went into our program at 12 months of age have not ended up with autism," Young says. "Now, they might not have anyway, but early signs are that we may be able to prevent progression to autism."

[…]

For the full article see http://www.abc.net.au/health/thepulse/stories/2009/10/15/2714894.htm

How a golden retriever named Galaxy became a dog star

CHRIS JOHNSTON, The Age

17 October 2009

Only a year or so ago the Weinstocks of East Bentleigh were thinking the unthinkable. Simon, nearly eight, their second son, might have to leave to live in care, for the sake of an already struggling family.

He is so severely autistic that he could barely talk. Simon was smashing his head through windows, not sleeping much and eating only white food. He was biting people and smearing faeces around the place. This was before Galaxy the dog arrived. Since then it has all changed.

Before the arrival of Galaxy, Simon was climbing manically and running away. The house had not yet been Simon-proofed. He would abscond into six-lane traffic on South Road. “A Houdini,” says his mother, Sarah. “An escapologist.”

Once, a driver tried to help but Simon jumped in the car and sat down and smiled and put the seatbelt on. The driver called the police. Simon started kicking the police car and screaming. The only way they could calm him, before someone from the neighbourhood who knew him intervened, was to put a police hat on his head and a breathalyser in his mouth.

“I love him,” says Sarah. “He's magnificent." She keeps his hair long and people often mistake him for a girl but he's a stunning boy with deep, glittering caves for eyes. "You could paint him," she says. "But he's of a different world and that's where he's trapped.”

Consider the rest of the family, too. Sarah is very large – obese – with attention deficit hyperactivity disorder. She can't move freely and has back pain. Eldest son Phillip, 10, is autistic as well, but not severely. Husband Michael has Asperger's syndrome and young daughter Jasmine, 4, is borderline Asperger's.

They're a loving family but it was always chaotic and often perilous. “There's nothing normal round here,” says Sarah. "This is a dynamic and tough household. We were overwhelmed and desperate.”

It came to a head when Jasmine was born and Simon was four and Phillip was six. Simon had not started at the Southern Autistic School in Bentleigh and the family did not yet have their nanny or helpers.

The questions about Simon posed unknowns. Can we look after him? Will he be all right? Would he ever taste freedom? How aware could he eventually become?

Then Sarah read about autism dogs for children. She tried to get one in Australia but couldn't (although they are available now from a charity in Bendigo) so she started the long process to get one from America because, four years ago, there had to be a circuit-breaker.

The family, with Sarah's father, Ephraim "Smiley" Cyprys, raised $20,000, mainly through Melbourne's Jewish community. The Pratt Foundation donated money to cover travel expenses to America — it was the late businessman Richard Pratt's last bequest, literally from his deathbed.

Galaxy cost $15,000. The family brought him back from Dayton, Ohio, in April, after three weeks of intense training with him. He came from 4Paws for Ability where he had already been trained for six weeks by prison inmates. The family love his name because they felt they went halfway across the universe to get him.

At the first encounter, Simon, who previously was scared of dogs, squealed with delight and patted the dog with his foot, then got in his kennel.

Now Galaxy is part of the family and they often wonder if the rangy, tender young field retriever knows exactly what he has got himself into. But everything feels like it has changed forever. In just six months Simon has developed dramatically. He has started saying more words and asking to go to the toilet.

[…]

For the full article see http://www.theage.com.au/national/how-a-golden-retriever-named-galaxy-became-a-dog-star-20091016-h17m.html

Lack of disability services puts families at breaking point

The 7.30 Report, Australian Broadcasting Corporation

Broadcast: 30/09/2009

Reporter: Mike Sexton

It's estimated more than one million Australians suffer from either a profound or serious disability including one in every 24 children. The burden of care falls heavily on families taking an emotional, physical and economic toll. Some in the disability sector believe many families are at breaking point and that the way disabled services are provided needs a radical overhaul including a national insurance scheme.

Transcript

KERRY O'BRIEN, PRESENTER: There are estimates that more than one million Australians suffer from either a profound or serious disability, including one in every 24 children. The burden of care calls heavily on family, taking an emotional, physical and economic toll.

Recently, two family tragedies have made headlines where disabled children have allegedly been killed by their parents. Some in the disability sector believe many families are at breaking point and that the way disabled services are provided needs a radical overhaul, including a national insurance scheme.

Mike Sexton reports.

MIKE SEXTON, REPORTER: For more than 20 years, Terry and Fiona Bradford have cared for their severely autistic son, William.

FIONA BRADFORD, PARENT: You can't leave him unsupervised. So he requires 24-hour, seven day a week adult supervision.

MIKE SEXTON: Terry Bradford gave up his career to spend his days cleaning, feeding and exercising his son. It's a decision that regularly leaves him exhausted from looking after an active young man with the mental capacity of a toddler.

TERRY BRADFORD, PARENT: We went through a period of a year with no respite virtually, and which meant that emotionally and physically we, you know … we hit a brick wall.

But we, you know, but we just keep going, because it's not an option - that's what we have to do.

MIKE SEXTON: There are half a million Australians who are the primary carers for a disabled person. While the majority have coped, there have been tragic consequence consequences for some.

[…]

For the full transcript see http://www.abc.net.au/7.30/content/2009/s2701288.htm

A genome-wide linkage and association scan reveals novel loci for autism

Although autism is a highly heritable neurodevelopmental disorder, attempts to identify specific susceptibility genes have thus far met with limited success. Genome-wide association studies using half a million or more markers, particularly those with very large sample sizes achieved through meta-analysis, have shown great success in mapping genes for other complex genetic traits. Consequently, we initiated a linkage and association mapping study using half a million genome-wide single nucleotide polymorphisms (SNPs) in a common set of 1,031 multiplex autism families (1,553 affected offspring). We identified regions of suggestive and significant linkage on chromosomes 6q27 and 20p13, respectively. Initial analysis did not yield genome-wide significant associations; however, genotyping of top hits in additional families revealed an SNP on chromosome 5p15 (between SEMA5A and TAS2R1) that was significantly associated with autism (P = 2 10-7). We also demonstrated that expression of SEMA5A is reduced in brains from autistic patients, further implicating SEMA5A as an autism susceptibility gene. The linkage regions reported here provide targets for rare variation screening whereas the discovery of a single novel association demonstrates the action of common variants.

More? See http://www.nature.com/nature/journal/v461/n7265/full/nature08490.html

Other links ...

http://www.eurekalert.org/pub_releases/2009-10/biom-gso100509.php

http://www.scientificblogging.com/news_articles/autism_gets_genomewide_study

http://www.physorg.com/news174140329.html

http://www.sciencedaily.com/releases/2009/10/091007131210.htm

http://edition.cnn.com/2009/HEALTH/10/15/health.genetic.autism/index.html?eref=rss_us

Mercury levels similar in autistic, normal kids

20 October 2009

By David Morgan

WASHINGTON (Reuters) - Children with autism have mercury levels similar to those of other kids, suggesting the mysterious disorder is caused by a range of factors rather than "a single smoking gun," researchers said on Monday.

The researchers at the University of California, Davis, initially found that children aged 2 to 5 with autism had mercury levels lower than other children because the autistic kids ate less fish, the biggest source of mercury that shows up in the blood.

But when the data were adjusted for lower fish consumption, blood-mercury concentrations among the autistic children were roughly similar to those developing typically. The children with autism had mercury levels in line with national norms.

The findings, published online in the journal Environmental Health Perspectives, come at a time when advocates including parents argue that mercury found in fish, dental fillings, vaccines and industrial emissions are responsible for autism.

The debate became more vehement this month after the U.S. Centers for Disease Control and Prevention said autism was more common than previously thought, affecting one in 91 children, including about one in 58 boys.

[…]

For the full article see http://in.reuters.com/article/idINTRE59I4W020091019?sp=true

Better diagnosis leads to higher autism rates

15 October, 2009

A study by researchers at Perth's Telethon Institute for Child Health Research has found that the rapid increase in the number of children diagnosed with autism spectrum disorders (ASD) in Western Australia reflects changes to diagnostic practices and services.

The research will be published in this month's edition of the International Journal of Epidemiology.

Research co-author Dr Emma Glasson said the study investigated factors behind the concerning increase in autism rates.

"We wanted to address community concerns as to why there are so many more young children being diagnosed in recent years with autism spectrum disorders," Dr Glasson said.

"While a true increase can't be ruled out, there is a very definite pattern that shows the increase coincides with changes to the way autism was diagnosed and the provision of funding for early intervention services."

The study found that in 1983 1.7 in every 10 000 children born in WA were diagnosed with ASD by age 8 compared with 53.4 per 10 000 children born in 1997, representing a 16.6% increase per annum.

From the late 1980s there was a parent-initiated drive towards more proactive early intervention services. In 1991 a new panel was set up to determine the eligibility of children for services. In 1994 the diagnosis of Asperger syndrome was introduced. In 1997 new funding was made available for early intervention for pre-school children.

Dr Glasson said the study also observed that children were being diagnosed at a younger age, reflecting better awareness and parents' willingness to access early intervention services.

From http://www.ichr.uwa.edu.au/media/1055

Autistic jobseekers 'written off'

The NAS says Jobcentre Plus staff lack understanding of autism

People with autism are condemned to financial hardship by poor employment and benefits support, a charity says.

The National Autistic Society (NAS) is calling for a national strategy to help people with autism into work.

NAS chief executive Mark Lever said people with autism experienced "anxiety, confusion, delays and discrimination" when using services.

The Department for Work and Pensions said it was "determined to provide the best support possible" to them.

Launching its "Don't Write Me Off" campaign, the NAS says a majority of the over 300,000 working age adults with autism in the UK want to work but only 15% are in full-time paid employment.

The charity says a key problem is a lack of understanding of autism among Jobcentre Plus staff, who determine eligibility for benefits and provide employment support.

It is calling for the government to introduce autism coordinators who would work with frontline staff, local employers and employment support services.

[…]

From http://news.bbc.co.uk/2/hi/uk_news/8303389.stm

Also see http://www.dontwritemeoff.org.uk/

http://www.guardian.co.uk/money/2009/oct/17/employing-adults-with-autism

Wave hello to the surf genius with Asperger's

At just 20, Clay Marzo is already seen as the most talented surfer of his generation. A new film explains how his condition could have given him a unique edge over his competitors. Guy Adams watches in awe

3 October 2009, The Independent (UK)

To see Clay Marzo drop into an enormous wave, carving under its barrelling lip then emerging, in a vibrant flash, to throw his surfboard into a series of elaborate leaps and twists, is to witness a jaw-dropping display of raw sporting talent.

Watch the professional surfer totter on to dry land, however, and an unfortunate transformation occurs. In the time it takes to shower and throw on a hooded top, he'll turn from swaggering athletic hero into an awkward, troubled recluse.

Sometimes, Marzo will sidestep autograph-seeking fans, rubbing his hands, or anxiously pulling at his hair. Other times, he might give a withdrawn TV interview that redefines the meaning of monosyllabic. Occasionally, he can even turn aggressive, or come across as just plain rude.

In truth, he's no such thing. Instead, Clay Marzo, who exploded on to the scene at Puerto Escondido in Mexico last month with his first pro victory, and is now being dubbed the most naturally gifted surfer of his generation, has a high-functioning form of autism called Asperger's syndrome.

The condition makes it difficult for the 20-year-old wunderkind to interact with other people. He finds crowds unnerving, conversation perplexing, and is unable to "read" emotion on someone's face. In social situations he is often – if you'll pardon the expression – a fish out of water.

Yet Asperger's is also the secret of Clay Marzo's incredible sporting ability. According to an acclaimed documentary called Just Add Water, it actually helps him succeed in the glamorous field of professional surfing. He is a unique talent because of the condition, rather than despite it. Some believe it could eventually make him the greatest surfer in history.

[…]

For the full article see http://www.independent.co.uk/life-style/health-and-families/features/wave-hello-to-the-surf-genius-with-aspergers-1797025.html

http://www.theatlantic.com/doc/200910u/autism-diagnoses

Letters

Dear A4,

Thank you for another very informative update. We really appreciate your good work.

Kind Regards,

Sarah

Dear A4,

You absolute champions.

Sitting here crying with gratitude and concern.

This is a very valuable document.

Jane

Reviews

Two DVDs from New Zealand on Autism Spectrum Disorders

Living with Autism

Living with Autism is a 48 minute DVD mostly of parents talking about their varied experiences.

The DVD discusses services in New Zealand. It talks about the need for early intervention, and a number of the approaches families choose in New Zealand.

Families report that their Government’s position is that there is little or no hope for a child diagnosed with autism. These families on the DVD reject this view: they actively sought and provided appropriate interventions for their children. And they report consequent benefits for their children.

The DVD omits the usual technical descriptions of autism or autism spectrum disorders preferring to give voice to families and their experiences.

Families talk about their experience with interventions including ABA and biomedical approaches. Some of the children have "improved dramatically" when their families have put in substantial efforts. It has a pretty strong self-help message.

The message calls families to action on behalf of the child/children with ASD. At times, the material is political and critical of mainstream services in New Zealand. Families talk about having to find and fund ASD interventions themselves.

Autism at School

Autism at School is described as "a video resource for teachers and parents in New Zealand". It has three parts: *The School Experience* (80 minutes), *Advice & Tips* (50 minutes) and students *Talking about School* with their parents (20 minutes).

Most of the material on the DVD is good. It starts with higher functioning and relatively articulate children in mainstream settings. It discusses support in the classroom.

The initial case studies are of primary school students. Then it shows some high school situations.

It shows special schools and satellite classes in mainstream schools.

Descriptions of the autism spectrum that say Asperger's Disorder is "mild" annoy me. Just ignore that bit. The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) says all Pervasive Developmental Disorders (PDDs) are severe. This DVD shows a student with Asperger's Disorder who spent years out of school and needs significant support in school. In my view, a disorder with such a profound effect is not a mild disorder.

The message is predominantly positive. But it tells it how it is; warts and all.

If you are interested in students with ASD, this DVD is well worth a look. It could be a useful resource for parents of students with ASD, and for teachers who are receptive to influences other than established dogma. Most of the content is quite relevant to people in Australia.

Reviewed by Bob Buckley. For more information on these DVDs please see www.southernmoon.weebly.com

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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