

July 2008
Vol. 6, No. 5



Media Release

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25 June 2008

\$190 million boost for children with autism and their families

All children aged six and under who are diagnosed with an Autism Spectrum Disorder (ASD) and are not yet at school will have access to up to \$12,000 in essential early intervention support, through a landmark \$190 million package funded by the Australian Government.

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The package is the first national initiative to help families deal with this challenging disorder and is a major breakthrough in support for children and their families.

Under the four year Helping Children with Autism package to be rolled out from next month, an estimated 9,000 children diagnosed with an Autism Spectrum Disorder will be eligible to receive up to \$6,000 per year for two years before they go to primary school.

Parents will now be able to choose the early intervention measures that best suit their child from a range of authorised service providers. And they will be supported by up to 40 new Autism advisors across Australia providing advice, information and practical help following diagnosis.

Because of the additional challenges they face, families in rural and remote areas will be eligible for an additional \$2,000 to help their children benefit from early intervention services, as well as training, respite and other resources.

Helping Children with Autism will give greater access to a range of early intervention programs including one-on-one intensive activities, behavioural therapies and tailored group and individual programs.

The package also includes:

- Medicare rebates for ASD diagnosis and 20 visits to allied health professionals such as occupational therapists and psychologists for children aged up to 12 years old;
- 150 playgroups specifically for families and children with ASDs;
- Professional development for 450 teachers and school staff to support students with ASDs; and
- Workshops and information for parents and carers of pre-school and school aged children with ASDs, including an ASD website.

In addition, the Government is establishing six new autism-specific child care centres as part of the broader Government commitment to provide up to 260 new child care centres nationally.

Today's announcement builds on the \$1.9 billion funding boost to disability support services in partnership with the States and Territories which will deliver more than 24,500 additional disability places, including:

- around 2,300 in-home support services;
- 2,300 supported accommodation places;
- 9,900 individual support packages; and
- 10,000 much needed respite places in a range of forms across Australia.

Bill Shorten has announced Autism gets \$190m boost

June 25, 2008

PARENTS of autistic preschoolers will receive up to \$12,000 over two years to help pay for early intervention programs.

The assistance is part of the Federal Government's \$190 million election commitment to helping children with autism, which was outlined today.

The package, which includes a rebate of \$6000 a year to fund early intervention programs, will be available to parents of children aged under six for the two years prior to school.

Up to 3000 families would be eligible for the rebate this year, parliamentary secretary for disabilities Bill Shorten said.

"Some of the behavioural therapies are very expensive ... but at an early intervention centre, where you've got service providers, we are optimistic that this will go a substantial way."

Mr Shorten said the package was "a re-configuration" of the previous Howard Government's election commitment to autism, which was matched by Labor during last year's campaign.

"The Howard Government was proposing a lot less into early intervention ... this is principally an early intervention package," Mr Shorten said.

"Early intervention makes a quantum difference in the quality of life for a child with autism."

Under the package, children up to the age of 12 will be eligible for Medicare rebates for diagnosis and 20 visits to allied health professionals.

There is also funding for development courses for 450 teachers to support students with autism and the appointment of 40 autism advisers Australia wide.

Families in rural and remote areas will also be eligible for an additional \$2000 to help access services.

The Government says this part of the package will help 9000 families.

Autism is a neurological disability with no known cause and effects an estimated one in every 160 children

Help for children with autism

Maralyn Parker. *Wednesday, June 25, 2008 at 05:14pm*

All children with autism under six and not yet at school will get \$12000 in early intervention assistance.

At last [here is something](#) that will really help.

And better still, parents get to choose what interventions they want to spend the money on.

The \$190 million package includes medicare rebates for diagnosis and 20 visits to therapists and psychologists for children up to 12 years old, new playgroups and even professional development for 450 teachers and support staff. It actually goes further than the Howard autism package famously offered - in that more younger children will have access to help.

Of course parents with older children with autism are watching enviously. Support in schools is hugely inadequate. And the reality is families can spend \$60,000 a year on help for their children of any age.

Also as some parents have pointed out the \$190 million has been announced before - what they want is some action !

But Parliamentary Secretary for Disabilities and Children's Services, Bill Shorten, obviously knows what is needed. This package will be well received.

For reader comments

see http://blogs.news.com.au/dailytelegraph/maralynparker/index.php/dailytelegraph/comments/new_help_for_children_with_autism/

Submissions to Parliamentary Inquiries

The Senate Community Affairs Committee is conducting its **Inquiry into Special Disability Trusts**. The [terms of reference](#) include ...

The following matters relating to special disability trusts be referred to the Community Affairs Committee for inquiry and report by 18 September 2008:

- a. why more families of dependents with disabilities are not making use of the current provisions to establish Special Disability Trusts;
- b. the effectiveness of Part 3.18A of the *Social Security Act 1991*;
- c. barriers in the relevant legislation to the establishment of Special Disability Trusts; and
- d. possible amendments to the relevant legislation.

The submissions can be downloaded from

http://www.aph.gov.au/Senate/committee/clac_ctte/disability_trusts/submissions/sublist.htm. A4's submission is the second one listed (see http://www.aph.gov.au/Senate/committee/clac_ctte/disability_trusts/submissions/sub02.pdf).

The House Standing Committee on Family, Community, Housing and Youth is holding an **Inquiry into better support for carers**. The terms of reference are ...

To obtain an improved understanding of the challenges facing carers and their support needs, the committee will inquire into and report on:

- the role and contribution of carers in society and how this should be recognised;
- the barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment;
- the practical measures required to better support carers, including key priorities for action; and
- strategies to assist carers to access the same range of opportunities and choices as the wider community, including strategies to increase the capacity for carers to make choices within their caring roles, transition into and out of caring, and effectively plan for the future.

Hopefully, A4's submission will appear on the website soon. The submissions page for the inquiry (see

<http://www.aph.gov.au/house/committee/fchy/carers/subs.htm>) says there is a delay in placing submissions on the website. In the meantime, A4's submission can be downloaded from

<http://www.a4.org.au/documents/CarerInquirySubmission080704.doc>

Thanks to A4's Steering Committee for preparing these submissions.

Convenor's message

Dear A4 member

In recent weeks we have learned more about how the federal Government will deliver its *Helping Children with Autism* (HCWA) package.

The HCWA package is a major step forward. With this package the federal government recognises people with ASD have distinct needs; needs that are not the same as those of people with other disabilities.

Three departments each have a part in implementing HCWA. They have taken three quite different approaches.

The Health Department was the first to get going. On the 1st November 2007, it published descriptions of new Medicare items¹ for the diagnosis and treatment of autism in children aged under 13 years of age. Some of us will get used to talking about MBS items 110-131, 135, 296-370 (except 359) and 289.

These items establish a process for funding PDD diagnosis via paediatricians and child psychiatrists. Previously, few Australian paediatricians were involved in the diagnosis of PDD. It seems unlikely that the items provide sufficient funds for the types of testing needed in a quality diagnostic process.

We hope this will improve access to fast and reliable diagnoses. Only time will tell whether this new diagnosis process improves on or replaces the existing systems that currently delivers diagnosis outcomes comparable to those in the USA and Europe. The existing process may not be as quick as we would prefer, but the evidence seems to suggest that these processes have been shown to be relatively effective. For many of us, ASD diagnosis has been expensive ... but there are many ways the cost issue could be tackled.

To use Health's new system for ASD/PDD diagnosis, parents may need to be firm with their GP about getting their referral to see a paediatrician in the first place. Families will have to insist on getting a referral, and not accept suggestions to delay to see what happens in their child's development. Families should consult a better informed GP if their GP won't refer them immediately to a paediatrician.

Once a child is diagnosed with ASD/PDD, the paediatrician will develop a "treatment plan". Paediatricians will use their relevant training and experience (which could be minimal?) to design treatment for the child's PDD. Health Department officials say that the paediatrician can ask the family of the newly diagnosed child for guidance and advice about what they want in their treatment plan. The paediatrician can refer the child to allied health professionals for up to 20 visits. The 20 items can only be used while the child is under 15 years of age.

The requirements are that the Medicare items must be delivered face to face. So they will be very difficult to include in best practice early intervention.

I have concerns about the capacity of the existing workforce in the allied health sector to meet demand. I know that in the ACT, there is no spare capacity in Speech Pathology. There are significant challenges ahead for the psychology workforce.

So far, A4's attempts to meet the Health Minister have been ignored. Her office has not responded to numerous requests for a meeting. The staff in the Health Department who we have met focussed purely on telling allied health professionals about the processes and administration of the new Medicare items.

In summary, we can commend the Health Department for getting its part of HCWA going by 1 July 2008. The Health Department still has a lot to do to establish effective health services for people with ASD/PDD.

The other two Departments involved in the HCWA package, FaHCSIA and Education (DEEWR) are working to get their HCWA in operation.

The Consortium that won the DEEWR contract continues to develop training material for teachers and families. The Consortium members are recognised groups

1

[http://www.health.gov.au/internet/mbsonline/publishing.nsf/Content/C77AF9BC0761216DCA25745F002F0ABB/\\$File/1%20July%202008%20Allied%20Health%20Book.pdf](http://www.health.gov.au/internet/mbsonline/publishing.nsf/Content/C77AF9BC0761216DCA25745F002F0ABB/$File/1%20July%202008%20Allied%20Health%20Book.pdf) pages 50-57

from within the ASD community, and it is consulting other groups in the ASD community.

At this stage we hope that the training material will recognise and address the real challenges in educating children with ASD, most of whom did not get best practice early intervention.

One of the biggest challenges for our education systems, and for those training staff to work in those systems, is how to address behavioural challenges associated with ASD when they occur in school settings. A4 is very concerned by the number of students with ASD who are excluded from school.

Initial signs are that the training will focus on inclusive schooling. It has yet to be seen whether the training material that they develop addresses the spectrum of needs associated with ASD. As well as advising on inclusion in mainstream settings, training in effective operation of ASD-specific education settings (that is, ASD units in mainstream schools and ASD-classes in special schools) would be appreciated.

FaCHSIA is responsible for the largest part of the HCWA package. It will oversee implementation of the following components of the HCWA package.

- Up to \$6000 per year per child for early intervention for 2 years, with an extra \$2000 for improved access for people from rural/remote situations.
- 40 autism advisors.
- 150 playgroups
- A program of National Workshops for families of children with ASD aged 0-6 years (see http://www.facs.gov.au/internet/facsinternet.nsf/disabilities/funding_workshop_autism.htm)
- six childcare centres — one in each state (see <http://www.facs.gov.au/internet/facsinternet.nsf/ca4cf882aebb6ca7ca256d01001a08a7/9d0523ce9295fc7cca25748a00159d01?OpenDocument>)

The early intervention component is the largest and perhaps the most challenging. Service will be delivered through a panel of providers. The recent advertisement said ...

As part of this package, funding will be available for families and carers of children diagnosed with ASDs, aged 0-6 years and who are not yet at school, to access early intervention services. This funding will help provide greater access to a range of high quality, evidence-based early intervention services, including one-on-one intensive activities and tailored group and individual programs.

FaHCSIA is establishing a panel of multidisciplinary early intervention service providers based on evidence-based best practice guidelines.

Service providers on the panel will be required to offer multidisciplinary services via a collaborative team or a consortium of providers that collectively provide the required services.

Interventions eligible within the context of the *Helping Children with Autism* package are:

- Behavioural Interventions;
- Developmental and Social Learning Interventions;
- Therapy Based Interventions;

- Family Based Interventions;
- Speech Pathology;
- Occupational Therapy; and
- Child Psychology

Personally, I applaud FaHCSIA's efforts to promote the formation of major service providers. If they are successful, it will be easier for families to work with a single service provider addressing the majority of their child's needs.

The problem is that there are very few services (if any) that currently resemble such a service in Australia. Existing service providers do not fit this model. They may resist the change. In some areas, it may be very difficult for existing service providers to come together as the Government expects.

Another issue is that some of the more prominent service providers came from a special education background. They may not fit into the proposed model as easily as the professional groups listed above.

The latest detail about FaHCSIA's elements of the package have just emerged. Hopefully I can look at their selection criteria in more detail for the next newsletter. Some questions have already emerged. If you have any of your own questions or comment on the package we'd like to hear about them.

Perhaps the biggest issue is the cost of a service that can be recognised as best practice. Few families can fund best practice early intervention for a child with autism. If they need to fund all but \$6,000 for their child's program so they can access the early intervention element of the HCWA package, then many will be unable to do so.

So far, we have not heard very much from the professional organisations. Very few professionals in Australia have relevant credentials. There needs to be a concerted effort to determine what training and qualifications people need to provide intensive ASD-specific services.

In the November 2007 election, Labor made a clear commitment to children with autism (see <http://www.alp.org.au/media/1107/msedutcshealoo160.php>, <http://www.a4.org.au/e07/Labor071116.png> and <http://www.a4.org.au/e07/Labor071116.pdf>).

Federal Labor will also ensure there is a greater focus on our children's healthy development through:

- ...
- Comprehensive early intervention and specialised child care services for children with autism.

Clearly, "comprehensive early intervention" means early intervention that meets fully the Government's description of Best Practice. This is a big commitment. It will not be easy to implement.

The Government's *Helping Children with Autism* package was never intended to achieve this outcome. It was always described as just a beginning.

The Government has yet to decide how it will deliver "comprehensive early intervention". While \$6,000 per year is a welcome contribution, it falls well short of providing each child with 20 hours per week of intensive autism-specific early intervention for a minimum of two years. Nor is Labor's plan for 6 specialised childcare centres likely to meet demand for childcare.

We must ensure Labor does not renege on its election commitment to children with autism.

The Helping Children with Autism package was said to be just the beginning. There is a lot more work to do. We need to ensure people with ASD have equitable outcomes in their adult life. There is a long way to go before this goal is realised.

Regards
Bob Buckley

20/7/2008

Aversives and physical punishment in Tasmania

The Tasmanian Premier and Education Minister told the state's Budget Estimates hearing that 'the Lovaas method' for children with autism involves 'physical punishment'. The transcript² reports the following was said.

Ms JAMES - The person you are talking about has had 12 months of the Lovaas method. One component of the Lovaas method is that it uses aversives, and that is not something that we use within our system. We do not physically punish children to educate them. The original Lovaas method uses aversives.

Mr BARTLETT - Yes, it does have physical punishment involved in it.

Mrs NAPIER - But it is a system that can and does work with some children.

Mr BARTLETT - It has physical punishment involved in it that we do not use.

Issues like this divide the ASD community: these issues are very fractious and can be deeply emotional. The Premier's claim sparked a major discussion in the A4 Steering Committee that diverted the group from much more important work. In the end, the A4 Steering Committee did not find any evidence that current practice that might be referred to as 'the Lovaas method' involved physical punishment.

The Premier and Ms James, a senior official in the Tasmanian Education Department, made claims that are false.

Ms James claims use of aversives "is not something that we use within our system." Ms James is not correct: the Education Department website³ says ...

Children who behave in an unacceptable way may receive a detention. When behaviour is more extreme, students may be suspended, excluded or expelled from a school or, in the worst case, prohibited from attending any government school.

...

Talk to your school principal about the expectations the school has of students and how misdemeanours are dealt with.

Education Department's guidelines describe punishments (aversives) that it uses for behaviour management; specifically detention, suspension, exclusion, expulsion and prohibition from school. And schools may subject students found guilty of misdemeanours to other punishments/aversives.

Ms James says "the Lovaas method ... uses aversives"⁴. We understand Ms James to mean that applied behaviour analysis (ABA) uses aversives in teaching young

² <http://www.parliament.tas.gov.au/HansardHouse/isysquery/c9de1fe4-4750-407c-949d-b2cc0043cb41/1/doc/hestamon3.htm>

³ <http://www.education.tas.gov.au/school/parents/attending/behaviour>

children with autism⁵. This also is false: the Lovaas method (or ABA) does not use aversives in teaching children with autism. However, some *aversives* (in the technical sense of the word — see below) may be used to address dysfunctional behaviour.

The Premier. Mr Bartlett said “it does have physical punishment involved in it [the Lovaas method].” This claim is false. If Mr Bartlett has evidence of anyone using physical punishment to educate a child with autism he should refer it to the relevant authorities for prosecution in the legal system.

Ms James says “We do not physically punish children to educate them. The original Lovaas method uses adversives.” While Lovaas’s original research involved slapping the thigh of a child with autism, physical punishment was not part of his practice by the time his work was published in 1987. However, the record shows it was not until October 1999 when the Tasmanian Government stopped corporal punishment in Tasmanian schools (see Martine Haley, *Upper House finally approves corporal punishment stand*, The Mercury, Hobart, 1 October 1999 or <http://www.corpun.com/ausc9910.htm>) ... over a decade after professionals voluntarily ceased using physical punishment in behavioural approaches for teaching children with autism.

The Premier implicates the families of children with ASD who choose such an approach and the professionals who provide services in using physical punishment in their child’s treatment and education programs. The A4 Steering Committee did not find or know of any evidence that reputable programs involving “the Lovaas method” use physical punishment as the Premier suggested. The family that Ms James referred to contacted Bob Buckley, A4 Convenor, and assured him that the “12 months of the Lovaas method” that her son received did not involve physical punishment. We believe the Premier’s implication is false.

A4 does not support or promote particular therapies. This matter is about parents/families of children with ASD being able to exercise informed choice in their child’s treatment and education without their government maligning and denigrating their parenting with claims they teach their children using physical punishment. It is about defending professionals whose aim is to help children with autism achieve better outcomes. And it is about better awareness through accurate information.

A4 wrote to the Tasmanian Premier (download a copy of our letter from <http://www.a4.org.au/documents/Tas080708.doc>).

In the meantime, the Premier was asked about his claims in Parliament on the 1 July and Ms Giddings, the Health Minister, was asked about it on 2 July. The transcripts⁶⁷⁸ are available.

⁴ generally, Hansard transcripts are sent to participants for correction. It does not inspire confidence in the standard of discussion when none of the participants told Hansard staff that the word is “aversives” ... without the ‘d’.

⁵ The Federal Health Department’s website says “Lovaas style intensive behavioural programs emphasise that aversives are no longer used, and findings by Sallows and Graupner (2005) indicate that such programs without aversives are effective for some children with autism.” ... see <http://www.foodsecretariat.health.gov.au/internet/main/publishing.nsf/Content/mental-child-autrev-toc~mental-child-autrev-beh~mental-child-autrev-beh-con>

⁶ <http://www.parliament.tas.gov.au/HansardHouse/isysquery/c9b27606-6a80-48d1-b204-cf40852ac974/1/doc/h1july1.htm>

⁷ <http://www.parliament.tas.gov.au/HansardHouse/isysquery/ab24c206-c967-4a94-a860-61f1e8d86b02/1/doc/h1july2.htm>

The Premier responded ...

Mr BARTLETT - ..., I take the issue of children on the autism spectrum within our system very seriously. That is why I have met with a whole range of bodies and continue to work with. I am committed to providing flexibility to parents and individual education programs for children with special needs, including those on the autism spectrum.

This Government wants to provide a range of methodologies. The provision of 40 hours of continuous ABA support to every child in Tasmania who is on the autism spectrum is not affordable for this Government. It is simply not affordable, it cannot be done. ...

and

Mr BARTLETT - While accepting that some parents will make choices about ABA and a modified ABA approach ... that does not include violence or retributive behaviour in operation within parts of the government system. We will never advocate a system that includes violence and I am clearly on the record as saying that. I will not support a system within Tasmanian government schools that includes violence.

It seems the Premier's statement does not accurately reflect the view of Autism Tasmania. The Autism Tasmania committee met and released a position paper⁹.

A4 is not aware that anyone asked the Tasmanian Education Department to provide 40 hours of anything within a 30 hour school week. We can agree that no amount of money could possibly achieve that. As Mr Bartlett says, "it cannot be done".

It is not easy to understand what Mr Bartlett is talking about. It seems he equates 'the Lovaas method' to the use of Applied Behaviour Analysis (ABA) in relation to children with autism. On 1 July, he escalated his claim from 'physical punishment' to 'violence'.

Several participants in the discussion may be equating "aversives" to "physical punishment" but these are not the same. Aversives are the subject of considerable debate and research in behavioural psychology. It centres generally on clinically dysfunctional behaviour.

In common use, "averse" or "aversion" mean dislike, possibly intense dislike. So an "aversive" is doing something to a person that that person does not like or finds unpleasant.

The aversives/punishment debate is much broader than ASD. While we would all want to live in a community that without any needs for punishment, most people do not expect governments will be able to close their prisons, cease speeding fines, etc. in the foreseeable future.

The technical meaning of "aversives" is more specific. It is discussed in Wikipedia¹⁰.

Aversives are unpleasant stimuli which induce changes in behavior through punishment; by applying an aversive immediately following a behavior, the likelihood of the behavior occurring in the future is reduced. ... It is not the level of unpleasantness, but rather the effectiveness the unpleasant event has on changing behavior that defines the aversive.

⁸ <http://www.parliament.tas.gov.au/HansardHouse/isysquery/fe4c2f5d-a15b-4742-9a1c-0536e7bb09c0/4/doc/h2july1.htm>

⁹ <http://www.autismtas.org.au/downloads/AT%20views%20on%20childhood%20intervention.pdf>

¹⁰ <http://en.wikipedia.org/wiki/Aversives>

In technical talk, the term *aversive* only applies where targeted behaviour *reduces*. Presumably the name for unpleasant stimuli that do not reduce unwanted behaviour is *abuse*.

The issue of which behaviours should be targeted needs careful and ethical consideration. Generally aversive methods should be restricted to targeting dysfunctional behaviour that warrant clinical attention. Aversives should only be used as the last resort for an existing dysfunctional behaviour.

Aversive is a very broad term. It is much more than physical punishment. For example, some people do not like being ignored. So for them, the practice of ignoring unwanted behaviour (extinction) is aversive but only if it reduces the unwanted behaviour. [Reinforcing/rewarding periods when unwanted behaviour is absent is a non-aversive alternative called “negative reinforcement” or “catching the child being good”; and can augment “extinction” to minimize its use as an *aversive*].

Discussion of *aversive* can be highly academic. Theoretically most people want *aversives* that involve clear dislike eliminated. Pragmatically, acceptable practice tends to look to balance the perceived level of unpleasantness/aversion, the undesirability of the target behaviour and the effectiveness of the method.

In Tasmania, Part 3 of the Disability Services Act 1992 (DSA) establishes an Ethic Committee with functions ...

to monitor programs and services relating to persons with disabilities to ensure that they are designed and administered so as to be as free as possible from aversive, restrictive and intrusive treatment practices

The law does not explain what it means by “aversive, restrictive and intrusive treatment practices”. Clearly, the DSA Ethics Committee does not prohibit school detention as aversive and restrictive practice. It seems it took until 1999 for corporal punishment to get banned in Tasmania’s special schools ... did the DSA Ethics Committee have anything to do with that?

The Wikipedia page on aversives provides links that discuss the history and ongoing debate about using aversives¹¹ and punishment¹². There are several pieces of commentary¹³ in the journal following the article on punishment.

One of the articles says ...

In 1972 the American Humanist Society awarded B. F. Skinner, their “Humanist of the Year” award. It was dedicated for his efforts to show how “a less punishing world” was possible. It was a controversial choice to say the least. ...

The article concludes ...

... Baer, Wolf, and Skinner have shuffled off for the big experimental space in the sky. ... Risley is now an advocate for exclusively positive practices and Lovaas has repudiated his use of aversives. Behavior analysts have almost entirely abandoned the use of physically aversive techniques for autistic children. Is this a happy ending then?

I would submit that the answer is “no”. Skinner argued five reasons exist that show punishment should not be used. One was shown to be false. The other four remain.

¹¹ <http://interverbal.blogspot.com/2006/02/less-punishing-world-contradictions-in.html>

¹² <http://www.pubmedcentral.nih.gov/picrender.fcgi?artid=1284409&blobtype=pdf>

¹³ <http://www.pubmedcentral.nih.gov/tocrender.fcgi?iid=124098>

Some important distinctions must be made.

1. There is no place for aversives in teaching new skills and knowledge. Any use of an aversive in an education setting should be limited to behaviour management and extremely carefully managed.
2. Students, especially students with ASD, may not respond as adults expect to behaviour management measures. The use of any intended aversive must cease if it fails in reducing a student's unwanted behaviour.
3. Ignoring behaviour analysis (for example, not knowing a behaviour management strategy is aversive) is unacceptable.

We have human rights

A book for self-advocates

Welcome to the power of human rights. This book is for people with developmental disabilities. You can use it to learn about your rights. You can also use it to talk with others about your rights.

When you speak up for yourself, you are a self-advocate. When you work together with others, you can make change happen. Welcome to the power of human rights!

...

Download it here ... <http://www.hpod.org/pdf/we-have-humna-rights.pdf>

Victorian Autism Plan - Consultation Summary

The May 2008 A4 Update had a link to the Victorian Government's report that it described as a Consultation Summary. A4 received numerous objections to the summary, particularly that it did not reflect their views and the view expressed in the meetings our members attended. A4 members felt betrayed by the process.

The A4 Steering Committee wrote a letter to the Minister. You can download A4's letter from <http://www.a4.org.au/documents/2008/vicplan/Vic080622.doc> or <http://www.a4.org.au/documents/2008/vicplan/Vic080622.pdf>.

You can download the Minister's response from <http://www.a4.org.au/documents/2008/vicplan/Vic080721response.pdf>.

If you live in Victoria and you are concerned, like we are, that the Government did not really listen to what the community said, then we encourage you to write your own letter to the Minister. In politics, your letters (or email) to the Minister on an issue like this make a difference. Contact information for the Minister is ...

Hon Lisa Neville MLA
Minister for Mental Health & Minister for Community Services
Level 22, 50 Lonsdale Street
Melbourne 3000

Email: lisa.neville@parliament.vic.gov.au

You could email a copy of your letter to the following members of the Government ...

Hon. John Brumby MLA, john.brumby@parliament.vic.gov.au
Hon. Jacinta Allan MLA, jacinta.allan@parliament.vic.gov.au
Hon. Daniel Andrews MLA daniel.andrews@parliament.vic.gov.au
Hon. Maxine Morand MP maxine.morand@parliament.vic.gov.au
Hon. Bronwyn Pike MLA bronwyn.pike@parliament.vic.gov.au

A very simple letter is usually best: you can just say you are disappointed that your message to the consultation is not reflected in the Government's summary.

Grandfather builds Web browser for autistic boy

This is from <http://apnews.excite.com/article/20080603/D912OC100.html>

John LeSieur is in the software business, so he took particular interest when computers seemed mostly useless to his 6-year-old grandson, Zackary. The boy has autism, and the whirlwind of options presented by PCs so confounded him that he threw the mouse in frustration.

LeSieur tried to find online tools that could guide autistic children around the Web, but he couldn't find anything satisfactory. So he had one built, named it the Zac Browser For Autistic Children in honor of his grandson, and is making it available to anyone for free.

LeSieur's quest is a reminder that while the Web has created important communication and educational opportunities for some people with cognitive impairments, computers can also introduce new headaches for families trying to navigate the contours of disability.

The Zac Browser greatly simplifies the experience of using a computer. It seals off most Web sites from view, to block violent, sexual or otherwise adult-themed material. Instead it presents a hand-picked slate of choices from free, public Web sites, with an emphasis on educational games, music, videos and visually entertaining images, like a virtual aquarium.

Other programs for children already offer that "walled garden" approach to the Web. But LeSieur's browser aims to go further: It essentially takes over the computer and reduces the controls available for children like Zackary, who finds too many choices overwhelming.

For example, the Zac Browser disables extraneous keyboard buttons like "Print Screen" and turns off the right button on the mouse. That eliminates commands most children don't need anyway, and it reduces the chance an autistic child will lose confidence after making a counterproductive click.

Children using the Zac Browser select activities by clicking on bigger-than-normal icons, like a soccer ball for games and a stack of books for "stories." The Zac Browser also configures the view so no advertisements or other flashing distractions appear.

"We're trying to avoid aggressive or very dark or complicated Web sites, because it's all about self-esteem," LeSieur said from Las Vegas, where he lives. "If they're not under control, they will get easily frustrated."

Autism generally affects a person's ability to communicate, and Zackary doesn't speak much. But his mother, Emmanuelle Villeneuve, reports that the boy can start the Zac Browser himself. He enjoys listening to music through the program and trying puzzles - things he always liked before but hadn't been able to explore online, she said from her family's home in suburban Montreal.

Perhaps most tellingly, while he still acts out aggressively against the TV, she said, he doesn't try to harm the computer.

LeSieur didn't create the browser by consulting with people who are considered experts in disorders on the autism spectrum. The small software company he runs, People CD Inc., essentially designed the Zac Browser to meet Zackary's needs, and figured that the approach would likely help other autistic children. Early reviews have been positive, though LeSieur plans to tweak the program so parents can suggest new content to add.

Several autism experts were pleased to hear of LeSieur's work, and not surprised that he had not previously found anything suitable for Zackary.

After all, the autism spectrum is so wide that a particular pattern of abilities or impairments experienced by one autistic person might be reversed in another. In other words, creating software that would work for huge swaths of autistic children is a tall order.

Indeed, the Zac Browser might do nothing for another autistic child.

That said, however, LeSieur's approach of limiting distractions and using the software as a confidence-boosting tool "is a very good idea," said Dianne Zager, director of the Center for Teaching and Research in Autism at Pace University. She said many autistic students tend to do best with educational materials that make unnecessary stimuli fade from view.

"Some parts of the Web have so much extraneous material that it can be distracting, and for the nonverbal child, there might not be an ability to negotiate that information," added Stephen Sheinkopf, an autism researcher at Brown University.

This is not to say the Web is necessarily barren for autistic children. James Ball, an autism-education consultant in New Jersey, said many children he works with enjoy Webkinz, where kids care for virtual pets. Others find chat rooms and instant-messaging a lower-anxiety way of socializing than talking to someone in person, he said.

But the Zac Browser might turn out to be the rare tool that can be configured to strike a chord with a wide range of autistic students, said Chris Vacek, chief innovation officer at Heartspring, a special-education center in Wichita, Kan. Vacek is considering using the Zac Browser at Heartspring.

One huge advantage is that the browser is free, while many assistive technologies cost upward of \$5,000 and work only on specialized devices. But Vacek, himself a parent of an autistic child, said the Zac Browser's best credential is that it appears to pass what he calls Heartspring's "acid test": It has a high chance of increasing a child's ability to do things independently.

"Let's hear it for grassroots innovation," Vacek said.

On the Net: The Zac Browser can be downloaded or run directly from <http://www.zacbrowser.com>

Asperger Syndrome - Seminar

August 25th-26th - Facilitator: Annette Joosten

Hello,

On August 25th and 26th Annette Joosten (Curtin University) will be in Melbourne to conduct a two-day seminar entitled "Asperger Syndrome: Effective Teaching Strategies and Positive Behaviour Support". As Annette is based in WA this presents a unique opportunity to attend an intensive and informative professional learning program delivered by a highly regarded expert in this field. While this seminar will be of great value to those in the education sector, health care workers would also benefit given the range of issues and topics to be considered. If interested in attending (one or both days) please access all program and registration details from the attached flyer. If you know of anyone else who would have an interest in this seminar please feel free to forward this on.

About Annette Joosten:

Annette Joosten has more than 20 years experience as an occupational therapist providing therapy, consultation and professional development in Victorian schools.

Employed full time in specialist and regular school settings, Annette has provided support for students with a wide range of learning needs, including Asperger syndrome and autism, and worked collaboratively with teachers and families. Annette has a Masters in Disability Studies (Special Ed. Faculty, Flinders University) and she is currently completing a PhD researching autism spectrum disorders and behaviour, (University of Sydney). Annette has presented at the World Autism Congress, a series of workshops in Thailand by invitation, and at many National, State and local conferences and workshops. Annette has published in the Journal of Autism and Developmental Disorders and a workbook of Social Scripts for children with autism. She is currently working as an Associate Lecturer at Curtin University, W.A. Annette particularly enjoys putting theory into practice to provide solutions to every day classroom and playground problems.

All the best,
Critical Agendas Pty Ltd
107 Mackillop St, Geelong, 3220
(PO Box 1427, Geelong, 3220)
Ph. 5229 3728 Fax 5223 8922

Tax deductions for dependents

Tax offsets

I have never known that my daughters disability was a tax deduction. Unfairly of course, the lifelong caring families deduction is far less than the deduction of caring for an aging parent. We might need a campaign to change this discrimination on lifelong caring families.

A child over 16 is deductible by \$745.00
A parent or spouses parent is deductible by \$1,489

Some of you might already know this but I did not. If you can share this information with all families who are carers in your address books it might assist them in a small way.

Flood the taxation office with deductions for dependents. I am surprised that I have never heard of this before

Here is the link on the ATO site.

http://calculators.ato.gov.au/scripts/axos/help/parent071.htm#More_than_one_dependant

Cheers
Nell Brown

Community Living Project

PUBLIC MEETING 29 JULY 2008

Come along and join with us to pave the way for a new, innovative, community living project for the ACT — where people with a disability are treated with dignity and respect.

- Do you live with somebody who has autism and/or an intellectual disability?
- Are you concerned about their future?

We think they should be able to:

- live in a safe, supported and happy community with peers
- enjoy a meaningful and satisfying life with access to employment or structured activities
- be treated with respect and be given opportunities to develop their full potential
- have ready access to medical/dental care
- be supported by a strong infrastructure of well trained, permanent staff

We're meeting to make this a reality

Please join us at the Public Meeting

When: 7 pm, Tuesday 29 July 2008

Where: Hellenic Club, Matilda Street, Woden

RSVP: Alison on 0406 333 904

If you are unable to attend the meeting we will be glad to send you further information. Please contact us on:
communityliving@optusnet.com.au

Making Parliamentary Friends of ASD

A goal of the Parliamentary Breakfast was to see if we could start a *Parliamentary Friends of Autism Spectrum Disorder*. Since the Breakfast I met with Senator Gary Humphries to progress this idea.

Senator Humphries has experience leading similar groups. He feels there is sufficient reason for having a distinct Parliamentary Friends of Autism Spectrum Disorder ... rather than trying to work through an existing group like the friends of Disability group. He is willing to help lead this group.

The purpose and function of such a group would be to improve awareness in political circles to help progress matters relating to autism spectrum disorders through the political process. The group would meet once or twice per year to share information.

Senator Humphries suggests we find a Labor backbencher from the House of Representatives to co-chair this group with him ... so both of the biggest parties are involved and there is someone from each House. "Friends of ..." groups are most effective when they are bi-partisan: when they have support from both sides of politics and function in both the House of Representatives and the Senate.

So it is over to you. Is your elected representative a Labor backbencher? Can you convince her/him to help people with ASD in this way? Is he/she keen? If you think she/he is keen, or if you want to get him/her interested then please call her/him up and ask. If she/he is interested please get him/her to contact Senator Gary Humphries and/or A4's Convenor, Bob Buckley (see contacts via email at the end of this newsletter).

If you want more information or advice on how to approach her/him, we can explain it on the telephone.

A4 needs you, as a member of A4, to help make this happen. You can do this on your own or take others from your local ASD support group with you. Do it soon ... please do not put it off.

In the news

Govt unveils early intervention payments for autistic children

Posted Wed Jun 25, 2008 4:00pm AEST

The Federal Government has unveiled how it plans to spend \$190 million in funding for parents of children with autism.

From next month, every child under six years of age who is diagnosed with a form of autism will have access to early intervention support to the value of \$12,000 over two years.

The Parliamentary Secretary for Disabilities, Bill Shorten, says the election commitment will help about 9,000 families over the next four years.

"This is real and it's going to assist parents. We want to help people through the journey of autism," he said.

"It is a start - I don't pretend it solves all the problems, I don't pretend it's all the resources which everyone wants - but I do honestly believe that this is the most significant national effort to support autism that's been attempted."

<http://www.abc.net.au/news/stories/2008/06/25/2285738.htm>

There were quite a number of stories ...

<http://www.smh.com.au/news/national/cash-help-for-autistic-children/2008/06/25/1214073342096.html>

<http://news.smh.com.au/national/govt-details-190-million-autism-package-20080625-2wmv.html>

<http://news.theage.com.au/national/govt-details-190-million-autism-package-20080625-2wmv.html>

<http://www.canberratimes.com.au/news/local/news/general/making-a-difference-for-children/798075.aspx>

<http://www.theaustralian.news.com.au/story/0,25197,23923684-5013871,00.html>

<http://www.theaustralian.news.com.au/story/0,25197,23920456-12377,00.html>

No school for autistic boy

Wed Jun 18, 2008 9:50am AEST, Updated Wed Jun 18, 2008 11:20am AEST

A Hobart woman is hoping the Tasmanian Premier will intervene in her fight to have her autistic son attend school.

Tania Gordon says her eight-year-old son Caden has not been to school since December 2006 when he was asked to leave the Hobart school he was attending.

Ms Gordon says Caden has now been refused entry to Cambridge Primary School, east of Hobart.

She says autism is a very isolating and lonely condition for a child and her son deserves the opportunity to mix with other children.

"Instead of it being shunted from Education to Health and then back to another one and everyone saying it's not our responsibility or anything," she said.

"For somebody just to stand up and say right what is in the best interests of this child and we will actually help you.

"Eventually I would like him to be able to go to a school, mainstream schooling."

In Parliament, the Premier David Bartlett was asked whether he believed all children with autism should be able to attend primary school.

Mr Bartlett said where possible, every child should attend.

"We're investing significant capital funds in the rebuilding of special schools right across the state," he said.

The Premier said funding for special needs children had more than doubled in the past five years.

Ms Gordon says her son is enrolled in Distance Education but has received no curriculum in the past 18 months.

<http://www.abc.net.au/news/stories/2008/06/18/2278117.htm>

<http://www.abc.net.au/news/stories/2008/06/19/2279428.htm>

Heroic deeds follow fear and loathing

Miranda Devine, June 21, 2008

...

Elijah Vetma, a year 7 student of Bellarine Secondary College in Victoria, has Asperger syndrome, a mild form of autism seen most often in boys with normal intelligence. They present as socially inept, absent-minded and slightly clumsy "little professors". They are unable to read social cues and tend to take language literally, so that phrases such as "pull your socks up" and "elbow grease" confound them. But they can also be brilliant, with speculation Michelangelo and Einstein were "aspies".

All his eccentricities have made Elijah, a sweet, sensitive boy, the perfect victim of bullies. At lunchtime he walks around by himself, lonely and desperate for a friend.

But this month, after a particularly gruelling day, he sat down and wrote a letter to his local newspaper, the Geelong Advertiser, to "help people understand how I and other people with disabilities feel about being bullied".

For more, see <http://www.smh.com.au/news/miranda-devine/heroic-deeds-follow-fear-and-loathing/2008/06/20/1213770920977.html?page=fullpage#contentSwap1>

Strip assault on autistic boy!

Herald Sun: Jen Kelly, Saturday, June 28, 2008

POLICE are shocked by a callous attack on an intellectually impaired teenager, forcibly stripped to his underwear in the street by two bullies.

Marc King, 14, was followed off a bus and grabbed by the older boys as he walked to his home in Croydon Hills, in Melbourne's east, just after 3pm on June 20.

"He came home in only his underwear and carrying his clothes," said his dad, Michael. "My older son asked what happened, and Marc ran into his room and cried."

Marc, who is autistic, later told his parents the two followed him off the bus on his way home from Heatherwood special school in Donvale. They had trailed him to his home, calling him names.

"Then about four houses from home, they grabbed him from behind, stripped him off, grabbed his top and his shirt and his singlet, then pushed him to the ground and took his tracksuit pants off him," Mr King said. "By that stage, he was crying and fairly distraught. Then they threw the clothes at him and said 'Run home, baby'."

Police hope to obtain video footage from the bus to identify the two boys, in school uniform and aged 15 or 16. Sgt Colin Andrews, urging witnesses to come forward, said: "It was quite callous."

Mr King said the incident was a huge setback for his son, who had only recently begun taking public transport alone. "What they've done is despicable, sickening," he said. "They obviously worked out he was intellectually impaired and an easy target."

He and wife Suzanne contacted the bus driver and learned the bus had video footage. The driver remembered the pair of teens as "ratbags".

Anyone with information should contact Crime Stoppers on 1800 333 000.

Autism centre opens at La Trobe

By Kate Bonsack, 1st July 2008 11:06:41 AM

ONE in 167 Australian children is affected with an Autism Spectrum Disorder and despite the condition becoming more common its cause remains a mystery.

La Trobe University, however, may soon have the answer after Australia's first autism research centre opened at the school's Bundoora campus last Friday.

Frustrated by the lack of funding and recognition the disorder requires, a Melbourne woman, Olga Tennison, donated \$500,000 to see the centre established.

In recognition of her generosity, the centre has been named the Olga Tennison Autism Research Centre.

Researchers at the centre will focus on advancing knowledge about the nature and causes of autism.

... for more see <http://www.senews.com.au/story/60840>



Direct approach ... Dr Cheryl Dissanayake is the director of Australia's first autism research centre at La Trobe University

Call for action after boy eats lead paint

Bridie Smith, July 11, 2008

Long-term fears: Ross Vinton, with parents Darren and Rosemary, is being treated for lead poisoning. Photo: *Michael Clayton-Jones*

PARENTS have called for children to be kept out of building sites that contain lead-based paint after an eight-year-old boy suffered lead poisoning at his Seaford primary school.

Blood tests show Frankston South student Ross Vinton's lead levels — at 0.98 millimoles per litre — are almost double those considered safe by the World Health Organisation.

Blood tests in 2004 showed his lead levels were 0.1, well below the normal limit.

Ross is autistic and one of his behaviours is pica, the eating of non-foods — including the flaky lead-based paint from his school's walls and ceiling.

Ross' father, Darren, is concerned his son could end up with an acquired brain disorder as a result of lead exposure.

"But this will have broader implications, because any school pre-1970s is a possible source of lead-based paints ... so for other children in the state this is an issue too," he said.

Read more ... <http://www.theage.com.au/national/call-for-action-after-boy-eats-lead-paint-20080710-3d78.html?page=-1>



Rebel with the soul of a clown

July 11, 2008

The Vines remain functionally shambolic, with frontman Nicholls a genuine loose cannon, but we wouldn't have it any other way, finds Andrew Murfett.

"I hate you!" Craig Nicholls, frontman for the Vines, is having one of his trademark stream-of-consciousness moments, during which, in the course of a long-winded answer (to a relatively benign question), he blurts out something off-topic but pointed.



This time, it just happens to be a swipe at a journalist. At me, in fact.

Tomorrow, the Vines release their fourth album, *Melodia*. Recorded in Los Angeles with producer Rob Schnapf (who recorded their million-selling debut from 2002, *Highly Evolved*), it's being pitched as a return to form. It's a snappy listen; 14 tracks lasting just 33 minutes.

Regardless of how *Melodia* fares, the Vines' story is a cautionary one. Seven years ago, the raw quartet sprang from south-west Sydney with a collection of demos so strong American label Capitol was prompted to pull out its chequebook.

Highly Evolved rendered Nicholls a star; it sold more than 1.5 million copies and scored the Vines high-profile slots at Glastonbury and Reading. They were the first Australian band in 20 years to land the cover of the US *Rolling Stone* magazine and their sound fitted neatly into the glossy garage rock aesthetic of their contemporaries: Jet, the White Stripes, the Hives and the Strokes.

Three years into their ascent, Nicholls was diagnosed with Asperger's syndrome, a form of autism which affects the sufferer's ability to function in social situations. And now the Vines' tumultuous history can be succinctly split into two periods: pre and post-diagnosis.

Finally, long-suffering bandmates and management had an explanation for his erratic behaviour.

But the damage was done. The band was splintered, their US deal in tatters and most goodwill with fans and media expunged.

Today, however - gathered in their management's Sydney offices before the video shoot for their comeback single, *He's A Rocker*, a fiery, commercially appealing, but brainless two minute stomper - the band insist they are looking forward. ...

Read more ... <http://www.theage.com.au/news/music/rebel-with-the-soul-of-a-clown/2008/07/10/1215658013594.html>

Special schools battle to meet rising demand

EMMA MACDONALD, EDUCATION REPORTER, 18/07/2008 10:39:00 PM

Canberra's special education services are being stretched to the limit because of an unprecedented increase in the number of students with disabilities, autism and very high needs.

The ACT Government is finalising this week the terms of reference for an urgent review of special education services, which will be completed by the end of the year.

ACT Education Minister Andrew Barr said he was concerned about the ACT's ability to cope with demand for services given a 20 per cent rise in the total number of all students identified with disabilities in the ACT during the past five years and a sharp increase in those with very high and complex needs.

Reasons for the rise include increased medical interventions and advances that have improved survival rates for babies with profound disabilities.

The ACT is also following a national trend towards increased autism diagnoses.

While the exact cause of this has yet to be established, an estimated 32 per cent of all students with disabilities also have autism, according to the latest ACT Department of Education statistics.

Former director of student services Kathy Melsom said in August 2002 that 1470 Canberra students were accessing special education.

This had risen to 1767 last year.

She also noted there had been a 30 per cent increase in the number of students choosing to attend mainstream schools with special support during the same period.

Read more ...

<http://www.canberratimes.com.au/news/local/news/general/special-schools-battle-to-meet-rising-demand/1060039.aspx>

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.

Update team: editor-at-a4.org.au

Editing: Bob Buckley edited this edition ...

Production: Helen Curtin (Qld) – proof-reading, Bob Buckley (ACT) – distribution.

A4 Steering Committee

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cnvnr-at-a4.org.au

Treasurer (donations): Cathy Ryan (Vic.)
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Members: Kelley Harris (Vic), Lionel Evans (Qld), Geraldine Robertson (Tas.), Mary Gebert (Vic), Katharine Annear (SA), Myrna Dominguez (NSW), Vicki McKay (Vic), Jasmine McDonald (WA), Peter Hill (NSW), Helen Steinhardt (Qld), Janet & Andrew McLean (WA), Leigh Michel (NSW), Raphael Murphy (SA).