

**February 2008**  
**Vol. 6, No. 2**

## Meeting the PM ...

The Community Cabinet meeting seemed like an opportunity too good to miss. We went onto the website and booked to attend. In wanting to talk about "autism and what it means for our son and our family" it seemed sensible to request a meeting with the PM and ask Minister Jenny Macklin to join us.



### Inside this Issue

Meeting the PM ...	1
Convenor's message	3
Welcome to Jack's Website!	8
I exist	8
from the Victorian State Autism Review Forum	9
Antipsychotics No Better than Placebo for	
Aggression in the Intellectually Disabled	10
Australian law and the UN CRPD	10
Snippets	11
The Age of ASD	12
A4 Contacts	12

### Disclaimer

1 While we have made every effort to ensure that  
3 information is free from error, A4 does not warrant  
8 the accuracy, adequacy or completeness of the  
8 information, graphics and materials in the A4  
Update. A4 does not guarantee that A4 Updates will  
be free from viruses.

A4 is not responsible for the results of any action  
taken or not taken on the basis of any information in  
the A4 Update, nor for any error or omission in that  
information. A4 expressly disclaims all and any  
liability and responsibility in respect of anything done  
consequent on the whole or any part of the  
information in the A4 Update. A4 shall not be liable  
for any loss, damage, liability, expense, cost or  
personal injury, whether direct or indirect,  
consequential or incidental, which you suffer, incur  
or are liable for, howsoever caused (whether due to  
A4's negligence or otherwise), arising from or in  
connection with your use of A4 Updates.

On 20 January 2008 our family (Janet, Andrew, Joshua & Georgia) had the privilege of having a 20 minute one-to-one meeting with the Prime Minister Kevin Rudd and Federal Minister for Family, Community & Housing Services and Indigenous Affairs (FaCHSIA), Jenny Macklin. In attendance were also the PM's Chief of Staff; Acting Secretary of the Department of Prime Minister and Cabinet (DPMC) and a few ministerial staffers.

During our one-to-one meeting we were able to introduce the PM and Minister Macklin to Joshua (and Georgia) and talk about life with autism, the lack of early intervention therapy services and some strategies to put autism front and centre of the Rudd Government's thinking.

In our 20 minutes with the PM and Minister Macklin we raised the following:

1. Setting a minimum number of direct hours of Autism Early Intervention therapy; (legislation needs to ensure direct hours of intervention reach the children and don't get eaten up in red tape.)
2. Issues with Labor's commitment to support all aspects of previous Federal Government's Helping Children with Autism package;
3. Labor's six specialised early childhood centres for children with autism – we recommended they establish 'Autism Centres of Excellence' in each Capital City and co-locate each of them with a university. (There are not enough trained professionals to provide the additional hours of intervention services needed.)
4. Need to know who in the ministry has responsibility for autism. Previous Federal Government never made it clear. Need strong linkages between Disability, Education & Health. We were advised that Hon Bill Shorten has responsibility for this issue.
5. National Autism Audit
  - a. Need to identify extent of ASD.
  - b. Should 0-6 years remain or is 0-8 more appropriate for Early Intervention.
  - c. Establish National Register (based on WA register).
  - d. National body – question effectiveness of current bodies?

PM asked Minister Macklin for clarification as to the extent of the number of children diagnosed with autism are the numbers as high as we say – her response was yes (thank goodness) he did not seem to realise quite how high the numbers were and did seem genuinely concerned.

We handed the PM a pack we had prepared with a letter from us and our story. He read it all and was certainly touched by what he read.

Janet made contact with the Secretary, FaCHSIA. Andrew made contact with the Acting Secretary of the Department of Prime Minister and Cabinet (DPMC).

The meeting took place during the Rudd Government's first Community Cabinet Meeting at Canning Vale Community College. In attendance were the Prime Minister, his Federal Cabinet and all the Secretaries (Department Heads) of all Federal Government Departments.

The PM was so impressed that in his closing remarks to the Community Cabinet Meeting of 600 people, he mentioned how meeting Joshua and our family had helped him focus on something he had not spent a great deal of time on before now. He did not reflect on any other meetings or questions of the day.

He appeared quite taken with Joshua and made an effort to seek out Joshua to say goodbye.

He also waved to Joshua from his car and Joshua actually waved to him back.

*Janet, Andrew, Joshua & Georgia McLean*

## Convenor's message

Dear A4 member,

For many of us, our kids have started a new year at school. We are at the business end of the annual commotion.

I now see these regular transitions forced on our kids also engulf us as parents in these periodic learning experiences ... mandatory lessons in what to avoid and what needs to improve in future.

Many schools do not recognise the distinct and individual needs of their students with ASD. Such schools hope to sort out problems as they arise, so there are many children with ASD who do start their year without their curriculum and the required resources in place. These schools do the same thing every year: they seem unable to learn, or should we conclude that they just do not care.

On the other hand, there have been a few reports of better preparation for the school year. A student who had been dreading her new teacher and a new classroom came home happy after the first day of school. The visuals she was comfortable with were already in the new classroom when she arrived and they were just part of the classroom ... they were there for everyone's benefit. Well done, that school and teacher.

Currently, I represent A4 on FaHCSIA ASD Advisory Group (ASDAG) in discussing the implementation of their *Helping Children with Autism* initiative. The Early Intervention part is the largest and significant concern. I am pleased to report that the various representatives of the ASD-community and service providers are remarkably united in their advice. We/they are all concerned that the government ensures children diagnosed with ASD can access 20+ hours per week of ASD-specific intensive early intervention and "there is no one program that will suit all children with autism and their families" (the same as the advice Prior & Roberts gave the government). Parents/families must be able to choose the types of early intervention provided for their child.

The government's initial plan offers a child with high needs a maximum of \$10K per year. Clearly, this would not provide a child with 20+ hours per week of ASD-specific intensive early intervention.

The ASD-community representatives are united in saying there is no equitable way to divide children under 6 years of age diagnosed with an ASD into 3 or 4 distinct levels of early intervention service. The representatives are also united and adamant on the issue of parent choice.

The representatives note that FaHCSIA's Inclusion Support Subsidy (ISS)<sup>1</sup> already funds young children with special needs up to \$20K per year to be included in mainstream childcare ... though few children with ASD access this scheme. Many children with ASD need effective intervention to prepare them to benefit from an inclusion scheme like ISS; and many young children diagnosed with ASD could benefit from therapeutic support/service<sup>2</sup> that were provided in a mainstream setting. But the ISS scheme does not support such a service ... so the government excludes many children with ASD from its early childcare inclusion scheme.

Representatives of the ASD community have suggested that children with ASD would benefit more if they were able to access at least 20+ hours per week of early intervention and

---

<sup>1</sup> See <http://www.facsia.gov.au/internet/facsinternet.nsf/childcare/services-ipsp.htm>

<sup>2</sup> opinions vary on whether therapeutic support or service delivered in a mainstream setting is compatible with "inclusion". Inclusionists ideology insists "segregation" is universally bad ... and that separating a child for individual therapy, to avoid distraction, is "segregation".

inclusion support. We expect this is more equitable and would deliver better outcomes for children who are not ready to be included in mainstream childcare.

Children with ASD who can be included in childcare can continue to use the ISS scheme for their support.

Many children with ASD need a level of ASD-specific intensive early intervention: while these children should be “included” appropriately, “inclusion”<sup>3</sup> alone does not meet their needs.

Much of the ASD community wants ASD to be recognised as a distinct type of disability with distinct needs including ASD-specific services. This need for ASD-specific services puts the ASD community in opposition to much of the disability sector. The provision of ASD-specific services sometimes requires that such services are separated from mainstream services. Inclusionists, a powerful lobby group, regard such separation as “segregation” ... and their view is that “segregation” is never good. Hence they expect that inclusive settings can meet all the needs of people with a disability, including meeting all the needs of children with autism/ASD.

Inclusion has been mostly about education.

Historically the educational inclusion of students with autism has been a fiercely controversial topic. In the past students with autism tended to be segregated from their peers and even from society as a whole. In Australia there appears to have been an increasing trend towards the inclusion of children with autism in regular education settings as part of the movement towards including all students with disabilities in regular education. Given the potential complexities of regular education settings for at least some students with autism, the lack of empirical investigation is of concern. It may be preferable to put the focus on providing students with appropriate education to meet their needs rather than assuming that inclusion in a regular classroom is the optimum placement for all students with autism at all stages of their education.

Roberts & Prior, p85

Discussion of Inclusion became very heated in the United Kingdom a few years ago. Reports from that time said ...

**Baroness Warnock, the architect of the drive towards teaching special needs children in mainstream schools, is to deliver a damning indictment of the system.** Mary Warnock, whose report on special education 25 years ago began the move towards greater inclusion, is calling for 'a radical review' of procedures. In a pamphlet to be published by the Philosophy of Education Society of Great Britain, she says the pressure to include pupils with special needs in mainstream schools caused 'confusion of which children are the casualties'. She says she wants to see an independent committee of inquiry set up to investigate how the policy is operating. She also calls for a review of the statementing process whereby parents can apply for a statement of their children's needs, claiming it is '**wasteful and bureaucratic**' and 'must be abolished'. Her U turn is confirmed just a day after the Conservatives called for a moratorium on special-school closures claiming the number of places has been reduced by 6,000 since 1997. She says support for inclusion springs from 'hearts in the right place' but describes its implementation as a '**disastrous legacy**'.

*The Independent*, June 9, 2005.

...

---

<sup>3</sup> Roberts & Prior (see Roberts, J. M. A., & Prior, M. (2006). *A review of the research to identify the most effective models of practice in early intervention of children with autism spectrum disorders*. Australian Government Department of Health and Ageing, Australia. p83) define “**Inclusion** in education refers to unconditional placement of students in regular education settings, regardless of type or degree of disability. Inclusion implies the existence of one comprehensive education system for all children.”

A leading children's charity has said it is alarmed by Baroness Warnock withdrawing her support for including disabled children in mainstream schools. Lady Warnock published a pamphlet setting out the reasons why she no longer thought such a policy of inclusion was healthy. Chris Osborne, policy adviser at the Children's Society, expressed concern at Lady Warnock's remarks. **'The Children's Society is alarmed at the negative picture of inclusive education that has emerged following Baroness Warnock's U-turn on inclusive education for disabled children.** Developing schools in a way that all children can flourish give disabled children an opportunity to belong and participate in their communities. Inclusion promotes familiarity and tolerance. It also reduces fear and rejection and improves achievement for all. **Despite the Government's commitment to embed inclusion in every school, discriminatory attitudes towards those with special needs still exist today.** Our vision of seeing children grow up together, not apart from one another, will only become a reality when the rights and needs of all young people are taken seriously.'

*PA News Wire, June 29, 2005.*

<http://inclusion.uwe.ac.uk/csie/june05.htm>

These are very polarised and extreme views. In my experience, views at the extremes are wrong. Rarely is anything so clear cut.

Inclusion has brought significant benefits for many children with disabilities. I hope we have learned to always aim to be more inclusive of children with a disability. Many inclusive practices improve the lives of people as intended ... and they can improve lives generally. For example, wheelchair ramps improve access for people with a disability ... and they make it easier to get prams and heavy equipment into buildings. We could view some recent methods in ASD treatment, like *incidental learning* and *natural environment training*, as inclusive approaches in discrete trial training.

But in relation to ASD, Inclusion is not all rosy. Inclusion is not the panacea or silver bullet overcoming all our differences and difficulties.

For example on the issue of bullying of children with ASD, the data clearly shows inclusion is not successful: children with ASD experience extraordinary levels of bullying. Data given to the SEN Inquiry in the UK showed "27% of children with autism ... in mainstream education are excluded at any one time" (see [www.publications.parliament.uk/pa/cm200506/cmselect/cmmeduski/478/478ii.pdf](http://www.publications.parliament.uk/pa/cm200506/cmselect/cmmeduski/478/478ii.pdf)). This is shocking information. Clearly inclusive education for children with ASD is not working if more than 1 in 4 students with ASD are excluded at the same time (it would be very interesting to know this data for the various education systems in Australia's states).

What classroom could or should include a 15 year-old student with untreated autism and minimal language; whose most appropriate way to occupy his time is masturbation? Certainly not the inclusive coeducation placement he was given. When is the burden on age-peers too big? Severe developmental delay leaves students like this with nothing in common with their peers. When is the diversity of need beyond the ability of a classroom teacher? For some students, there is no possibility of their learning anything positive from inclusion in a classroom meeting the needs of their age-peers. Never again in his life will such a student relate to adolescents collectively: he will spend the rest of his life in the company of adults. In such cases, an inclusive placement is not appropriate.

Inclusion dogma does not respect the preferences and needs of the people it aims to help. A child with ASD may need to be separated/segregated into a quiet space to overcome anxiety arising from the group setting. Some students with ASD prefer to be alone for some of the time; and their preference requires respect.

In my personal view, Inclusion is an important strategy: inclusive thinking and practice have delivered many significant improvements in how we treat, educate and support people with ASD. But inclusion is not the single solution and its methods are not always beneficial and appropriate.

Over time, Baroness Warnock moderated her views. She recognises now that some children with disabilities, including some of the children who are most severely disabled by their ASD, are not able to function adequately for extended periods in mainstream settings. She told the UK Parliamentary Committee ...

... I think the children with manifest disabilities, whom the severely autistic group would be among because many of them have no speech and so on, would already go to special schools. I doubt if many very severely affected children would be in a mainstream school, except in an autistic unit which is a separate thing within the school. I think the children who are least disabled and with less obvious disabilities are in a curious way the children who are worst done-by. Those are the children who have the kind of difficulties that make a large comprehensive school absolute hell. I know of one child for example who has been refused a statement because he has a high IQ. Autism is not a matter of IQ. This child is in complete misery and only goes to school when he is drugged with anti-depressants, but the invisibility of his difficulties makes it so hard for the parent.

Special schools, as they now exist, are not the answer either. Few special schools offer appropriate programs for children with ASD. We need special schools to include students with ASD properly. And we need better options generally ... probably based on responsibility sharing between health, education, community access & services, supported accommodation and supported employment.

When Jackson's mother (see *Welcome to Jack's Website* below) told me it took her 12 weeks to teach Jackson to carry a mailbag, a task he now enjoys as his job every work-day, I was left wondering what his education prepared him for. Clearly he could learn to carry things. Clearly he completed his education (and childhood treatments) without being taught this basic skill. What were they doing?

Another mother told me she asked that her son be taught to watch television but the school felt that was not an appropriate curriculum goal.<sup>4</sup>

Even fewer of the existing settings are suitable for students who are severely disabled by Asperger's syndrome/disorder. Schools and the rest of the community show very little understanding of or preparedness to address the needs of people with an average or above average IQ who are severely affected by their ASD.

Yes, there are success stories ... and we should appreciate them. We can celebrate the successes and learn from them. We can find successes in both mainstream and special education settings, in both private and public schools.

But there are far too many failures. For too many children and students with ASD, the existing systems fail to recognise and meet their individual needs. With so many students with ASD excluded from schools, denied equitable access to education and severely stressed by their circumstances, governments in Australia should now recognise the need and take appropriate action.

I see the Department of Education, Employment and Workplace Relations (DEEWR) component of the Government's *Helping Children with Autism* (HCWA) plan as a test. Will DEEWR rigidly adhere to inclusion dogma ... as their tender documents hint is likely? Or is Government ready to recognise ASD as a distinct disability with distinct needs — to recognise ASD is a spectrum that needs a policy and service spectrum in response? Will its 5-day teacher training and its parent education element preach inclusion dogma? Or will DEEWR's implementation team recognise that children with ASD have distinct and individual needs that demand service partnerships to provide extensive and ongoing ASD specific training, expert support and review/monitoring for frontline staff?

---

<sup>4</sup> Without the skill of watching television, a person needs other ways to occupy his (considerable) "idle" time. He is left with a very limited repertoire of mostly disastrous activities. He misses out on so much learning through video modelling of language, social skills and behaviour ... the behaviour at the very core of autism.

Will DEEWR's parent education component respect parent choice or pressure some of them into putting their child into inclusive placements inappropriately? Will it tell parents of children diagnosed with autism that experts recommend their child needed 20+ hours per week of intensive ASD-specific early intervention? And will it tell them that because they missed out, their children are less likely to experience the best outcomes possible? If not, what information will the service give these parents?

I hope children with ASD get as much benefit as possible from the treatment and education they receive; and subsequently find a place in their community in the longer term. My experience is that inclusive thinking and good inclusive practice brings benefits ... but that unconditional inclusion in education is not successful for a significant number of children with ASD. We must get better outcomes for all children with ASD.

In my role as Convenor, I regard it as important to let A4 members know my personal views ... and to listen to views of members who I aim to represent. I expect some of you will not agree with my personal position. I write this having already received an email (from a non-member) about ...

"your orientation and passions for segregation and against inclusion. I see that these are not unlike the good willed people throughout the past 100 years or so that were guided by a hope that a separate world could be created for the multitudes of the world's disenfranchised".

A4 is not just about my views. Members on A4's Steering Committee have views, as do our general members. Please feel free to let me, or our Steering Committee, know your views on these key issues. Good policy depends on broad discussion.

A4 represents varied members' views on early intervention for young children. I understand that A4 members generally agree that government needs to ensure a comprehensive range of appropriate services are available, and improvements are needed in all areas of service, for people with ASD.

Some parents want to be able to choose full inclusion for their child with ASD. Through its ISS scheme, FaHCSIA currently offers young children with a disability up to \$20K per year subsidy as up to 25 hours per week of support for full inclusion in mainstream childcare.

And A4 wants the ISS or a similar scheme to support better its clients with ASD and to support more children with ASD in appropriate childcare.

Many A4 members want parents to be able to make an informed choice about early intervention for their child. A4 asks that families who want early intervention can access at least 20 hours per week of ASD-specific intensive early intervention using a range of approaches to meet their child's needs. We expect parents will be given complete, accurate and impartial information about the range of approaches to early intervention. Parents should not be pressured into requesting any particular approach. Many parents prefer that early intervention is provided in an inclusive manner when that is possible. They prefer evidence-based approaches ... where "evidence-based" means quality research shows the approach achieves the planned goals and the service provider collects evidence that its programs deliver planned and measured outcomes for the individuals receiving their service.

A4 members want prompt diagnosis followed by ready access to early intervention (minimal waiting lists ...3 month max.). They want their child's development and education monitored to ensure the services they access are effective for their child.

Some A4 members want to be able to opt out of early intervention services. A4 advocates parent choice: parents can choose to opt out of early intervention.

I sincerely hope this reflects the range of views of A4 members on the issue of early (prior to school age) intervention.

Regards  
Bob Buckley

14/2/2008

# Welcome to Jack's Website!

Have you considered post-school options for a person who is severely affected by their autism? Jack's website includes information about JACKmail. JACKmail is a business that employs Jackson, a young man with autism.

Jack's website website (see [www.jacksonwest.org](http://www.jacksonwest.org)) says ...

JACKmail gives Jackson the opportunity to:

- be employed
- contribute to his community
- meet many small business owners, operators, employees and customers
- have a busy, active and interesting life
- be a positive example to others
- be an ambassador for other people with a disability

On the website, there is a link to the 60 Minutes story about JACKmail. The reporter just doesn't get it but if you need to know about post-school option this is worth watching.

## I exist

In the UK, the National Autistic Society is running a campaign for adults with ASD called "I exist". In 2007, it carried out a survey of adults with autism and their families, asking them about the support they receive, or would like to receive. More than 1,700 people responded, making it the largest UK survey of its kind.

The results reveal a stark and often desperate reality, where the majority of adults with autism are not receiving the support and services they need.

- 63% of adults with autism do not have enough support to meet their needs.
- 60% of parents say that a lack of support has resulted in their son or daughter having higher support needs in the long term.
- A third of adults (33%) say they have experienced severe mental health difficulties because of a lack of support.
- Over 60% of adults with Asperger syndrome or high-functioning autism have struggled to receive support from their local authority and/or health service. Of these, 52% were told that they do not fit easily into mental health or learning disability services.
- 61% of adults rely on their families for financial support and 40% live at home with their parents.
- 92% of parents are worried about their son's or daughter's future when they are no longer able to support them.

See <http://www.autism.org.uk/iexist>



## from the Victorian State Autism Review Forum

A family, with their youngest diagnosed with autism at age 2.5 yrs, was told that they would not be able to access autism early intervention, but that the good news was that their child would be able to be put on a waiting list for **“specialist speech therapy, where he would receive a comprehensive intervention program”**, the father told 100 parents, carers and state bureaucrats, his harrowing story. The family waited for the government funded agency that refused intervention, to call back and after waiting four anxious months, the family phoned the service. The family was told that the waiting list was 18 months, a piece of important information the service provider failed to tell the family 4 months earlier.

The father spoke of his disappointment and disillusionment at the state government and the agency that his son was left to “languish for many months without intervention.”

He related how he paid for private speech therapy, therapy his non verbal, profoundly disabled autistic son was unable to access through the government agencies. He told of how non autistic children with the need for speech therapy were able to access services within 4 months of being placed on the waiting list, yet his child with autism was unable to access the same help.

The family is bitter that the agency and government representatives wasted their time and their child’s potential.

The family then contacted the Royal Children’s Hospital out of desperation, as they witnessed their child slip further into his autism. The hospital told the family there was no funding available to treat autistic children and was unable to help. They contacted Latrobe University to recruit students from the only university that educates speech language pathologists, asking for help, and were promptly told that they were not funded to treat autistic children.

The father told of his dismay and curiosity as to why the professionals were unable to see the autism in their 2.5 year old son. “We had a GP, a maternal child health nurse, Pre School; child care service and no-one saw my child’s lack of speech and obvious developmental delay as being abnormal. I find that appalling,” he said.

“Our son was diagnosed by a speech therapist we employed, and she was able to tell us within 20 mins that he was autistic,” said the father. The family found out about Travencore, the autism assessment unit attached to the Royal Children’s Hospital Melbourne, through a family friend. They contact Travencore. Travencore refused to provide a multidisciplinary comprehensive assessment because he had already been given a diagnosis by the SLP. The family formally complained to the Health Services Commission who wrote to Travencore. The service made contact with the family expressing that they had not understood the family’s urgency about receiving a comprehensive assessment, and put the child on a waiting list, where he remains to this day: 14 months on, still with out a multidisciplinary assessment.

The family had their child assessed privately through a child psychiatrist and paediatrician at their own cost.

The family sold their home, the roof over their head and their financial security to fund an intensive behavioural based home program, with people coming in on a daily basis to provide intensive intervention. The family agreed that this provided their child with the best chance of a better outcome, rather than to be left to languish on the waiting list scrap heap.

### HOW HARD DOES IT NEED TO BE?

# Antipsychotics No Better than Placebo for Aggression in the Intellectually Disabled

See <http://www.medpagetoday.com/Psychiatry/GeneralPsychiatry/tb/7849>

This news item says

*At no point was placebo significantly worse than risperidone or haloperidol, nor was there a difference in response for the small group of patients with autism spectrum symptoms.*

In the last budget (see [www.ato.gov.au/budget/2007-08/bp2/download/bp2.pdf](http://www.ato.gov.au/budget/2007-08/bp2/download/bp2.pdf) on p247 ... just search the document for "autism") our government added "Risperdal Quicklet® for the treatment of behaviours associated with autism in children and adolescents" to the Pharmaceutical Benefits Scheme (PBS).

Typically people assume that a placebo has no effect so there is no need to give a placebo: they just don't bother to do anything. This is contrary to the evidence about placebos. Surely, to get the required result we still need to give the placebo.

An ASD parent, physiotherapist and medical researcher said ...

This is an interesting study and one where we have to be careful in the interpretation. One of the major drawbacks is that it doesn't have a no treatment group which makes it difficult to say there was a placebo effect as more likely there was no effect for any of the interventions (i.e. the placebo was equally ineffective). Having a no treatment group gives you some idea of the progression of the disease. There are a number of biases that come in with a study like this. Regression to the mean is probably the most powerful influence, in that aggression levels probably go up and down, you are most likely to intervene when the aggression is up and as a matter of course it goes down (maybe no matter what you do). Also in big centre trials there are some selection bias where people recruiting subjects will over estimate scores to get someone included in the trial and on next examination they are not so bad.

A good book on placebo effect is by Dylan Evans "The Belief Effect" and certainly belief on both the giver and the recipient is important.

Do Doctors prescribe placebo's? Well all those antibiotics for viral infections probably fall into this. However probably more important than the actual prescription is the social contract where the patient feels respected and assured by the doctor that they understand what is wrong and the course of action described by the doctor will make them better.

## Australian law and the UN CRPD

The Australian Government contacted A4 and asked whether A4 felt the Government should ratify the United Nations Convention on the Rights of Persons with a Disability (UN CRPD). Information on the consultation is available at <http://www.ag.gov.au/disabilityconvention> and [http://www.ag.gov.au/www/agd/agd.nsf/Page/Humanrightsandanti-discrimination\\_ConsultationonthePossibleRatificationoftheUnitedNationsConventionontheRightsofPersonswithDisabilities](http://www.ag.gov.au/www/agd/agd.nsf/Page/Humanrightsandanti-discrimination_ConsultationonthePossibleRatificationoftheUnitedNationsConventionontheRightsofPersonswithDisabilities).

The A4 Steering Committee discussed the issue briefly. This issue is a challenge as Steering Committee members have no legal qualification and limited legal experience.

The Australian Government, especially through HREOC, argues that its discrimination laws provide the required protection.

The A4 Steering Committee wrote back (see <http://www.a4.org.au/documents/AG080227-uncrpd-response.doc>) saying ...

We believe Australia should ratify the treaty and enact its provisions and protection in Australian law.

Unfortunately, the experiences of members of Autism Aspergers Advocacy Australia (A4) is that Australia does not have laws and a legal process to promote, protect and ensure human rights. ... In these circumstances, it is hard to see Australia's ratification of the various United Nations human rights treaties as anything more than a cynical exercise in public relations.

...

Were Australia to truly enact the provisions of the UNCRPD, young children would have access to appropriate ASD-specific treatment and rehabilitation for their autism. This would mean that the money being spent on younger children with autism would be more effective. Outcomes for people with autism and their families would improve; and service and support needs and costs would be reduced. People with autism and their family members would have a better chance to become productive members of our community.

Autism Aspergers Advocacy Australia asks that the Government enact in Australian law the provisions and protections of the UNCRPD.

Australia does not protect its citizen's human rights. In the matter of *Faure* (see [UN Doc CCPR/C/85/D/1036/2001](#) (31 October 2005)) Australia is found to breach Article 2(3) of the ICCPR as "Australia does not provide a general mechanism to challenge laws that violate human rights". The NSW Council for Civil Liberties (see [http://www.nswccl.org.au/issues/hr\\_violations.php](http://www.nswccl.org.au/issues/hr_violations.php)) says

*Since 1990 the UNHRC has heard almost fifty complaints against Australia. In seventeen (17) of those cases, the UNHRC found that Australia violated ICCPR [\[International Covenant on Civil and Political Rights\]](#) rights.*

Australian laws do not protect the right of people with ASD. Specifically, ...

- the High Court of Australia decided (*Purvis v NSW*) anyone can discriminate against a person whose behaviour (due to their disability, such as ASD) is deemed unacceptable ... it is OK (lawful) to mistreat a person with a disability exactly the same as someone might mistreat a hypothetical person with no disability (hence has no protection in the law from discrimination) who behaves none-the-less like someone with behavioural dysfunction (for example, pretends or otherwise behaves similarly to someone with an autism spectrum disorder).
- ACT Discrimination Tribunal decided (*Woodbury v ACT Government*) that the ACT Government can lawfully discriminate against people with autism spectrum disorders (or people with a disability, generally) in any way it likes.

In Australia, you can complain to HREOC about human rights violations. If HREOC investigates and feels your human rights have been violated, then HREOC might write a note to the Attorney-General, a member of the Government. This may not help if your complaint is about the Government or one of its agents/agencies.

You can then complain to the United Nations. But should you win there, the Australian Government may just ignore an adverse finding of the United Nations.

Ordinary Australian citizens have no human rights. As yet there is no sign Australian law will do any better for Australians with a disability.

## Snippets

### ***Autism Costs the UK £28 Billion A Year***

According to new research commissioned by the Foundation for People with Learning Disabilities, the annual cost of autism to the UK is just under £28 billion...

To read the full article, please go to: <http://www.medicalnewstoday.com/articles/88640.php>

### ***A model for team sport***

Participation in team sport is a challenge for many people with ASD. Here is a link to some video that shows an approach that clearly works for a range of children with disabilities.

<http://www.youtube.com/watch?v=Ni1GZdCzFpw>

## **The Age of ASD**

Recently, The Age newspaper in Melbourne published a series of articles on autism spectrum disorders (ASD). These are factual and informative stories.

Recent stories include:

***Barriers fall as Jack finds a voice***, Denise Ryan, February 11, 2008

See <http://www.theage.com.au/articles/2008/02/08/1202234170776.html>

***A is for autism***, Denise Ryan, February 11, 2008

See <http://www.theage.com.au/articles/2008/02/08/1202234170773.html>

***Autism advocate leads by example***, Denise Ryan, February 18, 2008

See <http://www.theage.com.au/articles/2008/02/16/1202760614284.html>

***Life in the goldfish bowl***, Denise Ryan, February 18, 2008

See <http://www.theage.com.au/articles/2008/02/16/1202760614287.html>

**Minister aims to put autism services back on national agenda**, February 25.

No link yet!

***Fight for a different normal***, Denise Ryan, February 25, 2008

See <http://www.theage.com.au/articles/2008/02/22/1203467395755.html>

I congratulate The Age on the coverage above of ASD.

The following story is less positive. It could easily have pointed out that Mr Amundsen has complex neurological and mental health issues that were undiagnosed and not addressed.

***Brisbane teacher jailed for bomb threats***, February 25, 2008

<http://news.theage.com.au/brisbane-teacher-jailed-for-bomb-threats/20080225-1uko.html>

## **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](mailto:editor-at-a4.org.au)

**Editing:** Bob Buckley edited this edition ...

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

### ***A4 Steering Committee***

**Convenor:** Bob Buckley (ACT)  
[cnvnr-at-a4.org.au](mailto:cnvnr-at-a4.org.au)

**Treasurer** (donations): Cathy Ryan (Vic.)  
[treasurer-at-a4.org.au](mailto:treasurer-at-a4.org.au)

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