



# UPDATE

**A4 Autism Aspergers Advocacy Australia**

**August 2007  
Issue 4**

## **Paying the price**

### **Parenting an autistic child**

*Jasmine Smith; June 8, 2007*

“HELLO. I'm sorry you don't qualify for Department of Ageing, Disability and Home Care assistance. Records show that your private child psychologist reported that your child can speak and his IQ is not under 75. We cannot case-manage you or offer you funds. Have we sent you our handy-dandy list of places to go, things to do?”

Several times. Things to subscribe to and stuff for autism cost money and are spread from Carlingford and North Rocks and Forestville and Putney and Peakhurst and Campbelltown and Woop Woop. Nothing accessible by public transport with toddler in tow, you understand.

Indeed. The child speaks because we have scrounged \$20,000 for private speech therapy, occupational therapy and more, while on a public health waiting list and riding taxis to the therapy groups. When not managing the toddler, I campaign for autism therapies to be put on Medicare.

The department is right. We are well-off. My husband has a job at the moment. He didn't for five years. That's Asperger's for you. The house is weatherproof and we own it. It has needed renovation since 1970, so we cannot sell, mortgage or rent it out. What are we complaining about?

Nothing really. Just autism. A sort of big nothing. Your child watches shadows and fluttering leaves when he should be watching the rest of his soccer team. He does a teapot dance facing

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away from play at the far goal when he could be striking the ball. He is a bit slower than the others.

His chances of living independently, being employed and thriving socially are diminishing with every year that he doesn't receive any sort of therapy. The education system says we're ready for the mainstream; which is odd, considering that my son is nearly seven but has yet to make a friend - unless you count sitting on kids or kissing Jack. Apparently, saving money and sticking to the Board of Studies curriculum is more important. The school says we're doing well enough and should be happy with that. They won't have to live with him when he is a maladjusted, rejected 25-year-old.

We are paying for private therapy for half the family because of the grief of autism. Moreover, we were a bit preoccupied when the only relative living locally, my brother, started making cries for help. We have hardly had time to grieve since he committed suicide.

We don't qualify for autism therapy or the department's help. So what do we do, buy lottery tickets? Shame the odds are longer than the incidence of autism!

## **It's TAX TIME**

### **Have you given tax rebates a go?**

Does your family regularly spend more than \$1500 on medical/educational expenses every financial year which cannot be reimbursed through any other means? For most families who have a child with an ASD the answer would be a resounding YES! Many of us who have tried medical and educational interventions with our children have found that they are enormously expensive and that there are limited ways to regain any of these funds.

Some years ago our accountant alerted us to a tax rebate of 20c in the dollar that could be requested at tax time for any medical expenses incurred over \$1500 which could not be reimbursed in any other way (such as through health insurance, Medicare etc.). It included those gap amounts which were not covered when claims are made through insurance and Medicare. It also included Dental expenses and Orthodontics not covered by insurance. We were told that the expenses had to be incurred under the direction of someone in the medical profession and that we had to furnish a paper trail to prove the expenditure made. My son is now nineteen years on age and over the years we have had none of our claims rejected, including phone consults with doctors in the States and expensive imported drugs.

Since then there has been an upgrade to the scheme whereby parents can claim the same 20c in the dollar rebate for behaviour therapies, aquatic therapy, music therapy and others - the key being to have a referral from a qualified medical practitioner. The treatment has to be directed by the doctor but not necessarily carried out by that doctor. More details can be gained from the following Australian Tax Office link:

<http://www.ato.gov.au/individuals/content.asp?doc=/content/19181.htm&page=2&H2>

And see the following decision:

<http://law.ato.gov.au/atolaw/view.htm?rank=find&criteria=AND~Medicare~basic~exact:::AND~benefits~basic~exact&target=JA&style=html&sdoid=AID/AID2001182/00001&recStart=1&PiT=99991231235958&recnum=3&tot=533&pn=ALL:::ALL>

Finally seek advice from your accountant at tax time and alert him to this rebate if he is unaware of its existence.

Jasmine McDonald.

## Disability Support for Young Adults

Centrelink has recently tightened up eligibility for the DSP. If you can help an older child/ young adult get on to the pension it will serve to take away some of the pressure of looking for work.

People have to have support from their GP or Specialist and have to see a Commonwealth Medical Officer for an assessment for eligibility. There is also an assessment called a Job Capacity Assessment which will determine how many hours a week they may be able to work - if they determine the person could work more than 15 hours a week they will not be eligible for the DSP.

They will need to outline the impact of all conditions on their daily living and do this from a worst case scenario. People are often advised to think of their worst day and then fill out the forms from that perspective because that is when you need the most support and that is your optimum level of support. The Doctor will have to support this level of functioning in the Treating Doctors Report.

A gap year between school and university can be good as long as they keep occupied - perhaps volunteer work or a special project. If they do a Centrelink approved activity and don't drive they may be eligible for Mobility Allowance which is an extra payment per fortnight to cover transport costs for people with transport issues.

Hope this info is helpful. (name withheld)

## Convenor's message

Dear A4 member

I guess it's my own fault for being an optimist. I keep being surprised at how dysfunctional governments are.

Increasingly, it looks like the Government is deferring CSTDA negotiations until after the election. It is very unlikely this will benefit people with a disability.

As another example, I hope when I write to government Ministers that they will give me a fair hearing; that they will read what I write and respond. Last December I wrote to the Prime Minister and a bunch of other Ministers. As yet none have replied (Yes! That is none ... not a single one). In some cases I've reminded them, their advisors and people in their departments that they have not yet replied.

Last month I wrote a series of Freedom of Information requests asking for all the information and documents relating to and arising from my letters. Maybe we can find out what the Ministers and their departments do with our letters. Is there a record that the dog ate their homework or did someone decide that people with ASD do not deserve a response? Or did they all just forget ... repeatedly?

We should know the reasons within a month.

Locally, I grew tired of the ACT Government refusing to discuss needs and services with representatives for people with autism and their families. I was naïve and optimistic. I thought that the Government's legal process would be slightly fair and might help. I hoped to get the legal system to address issues relating to early intervention for children with autism.

But the ACT's legal process took more than seven years ... and avoided any decisions relating to early intervention for children with autism. And it avoided decisions about our complaints. Basically, the legal processes in the ACT are broken.

The ACT Attorney-General refuses to meet to discuss these matters. The ACT Government does not care whether its legal processes work for people with a disability. So far, the shadow AG also remains uninterested in legal protection for children with autism.

We hear lots about the rights of various groups in our country - so far human rights groups and Australian legal professionals have proven completely disinterested in protecting the rights of innocent and especially vulnerable Australian children.

So without any legal assistance, I submitted my personal human rights complaint about the human rights of children with autism in the ACT to the (federal) Human Rights and Equal Opportunity Commission (HREOC).

A HREOC officer called me last month. A major part of the conversation was about trying to get me to take my complaint elsewhere ... and to canvas grounds for ruling that my complaint is outside HREOC's jurisdiction. Clearly, HREOC wants to make my complaint someone else's problem (an SEP). I expect they will make such a ruling ... on some ground or other. I believe it is within their discretion to decide to investigate such a matter on their own behalf ... but it is as extremely unlikely HREOC will decide to inquire into the rights of people with autism.

Declaring something a SEP is a favourite method in modern administration.

So far, all government agencies at both state and federal level regard treatment and rehabilitation services for people with autism as a SEP. Government agencies that are meant to overcome such a difficulty, such as the ACT Discrimination Tribunal and HREOC also want autism to be a SEP.

Clearly, existing legal systems will not force governments to act to benefit people with autism. But I remain hopeful that raising the needs of people with autism in the legal system will get government attention ... and help convince government that people with autism have serious needs and that we are serious about having their needs met.

People in Canberra are not the only ones taking legal action. A report in The Age says at least a dozen families are taking legal action (see <http://www.theage.com.au/articles/2007/07/24/1185043115570.html>). I hope the legal system in Victoria works better than the one in the ACT and federally.

On a more positive note, the ABC ran a story on siblings of children with a disability (see <http://www.abc.net.au/7.30/content/2007/s1986137.htm>). Autism is mentioned specifically including some quite powerful footage. I thank the Bradford family for showing the public a little of what their life is like. And it is good that our families are reminded to balance their capacity in meeting the needs of all their children.

Quite a few A4 member's email addresses are no longer working. Please remind people you know to update their email addresses if you hear they no longer receive A4 Updates. It is very easy to forget an A4 membership when your email address changes, but we have no way to keep in touch.

It is easy to update the email address that A4 uses to send you Updates: just use the membership form, the same as when you join up. Please ask your friends, relatives and contacts to join A4. More members means more effective lobbying of the federal Government.

I feel like media cover of ASD has stepped up a level in recent times. Congratulations to all involved. Please keep up the good work.

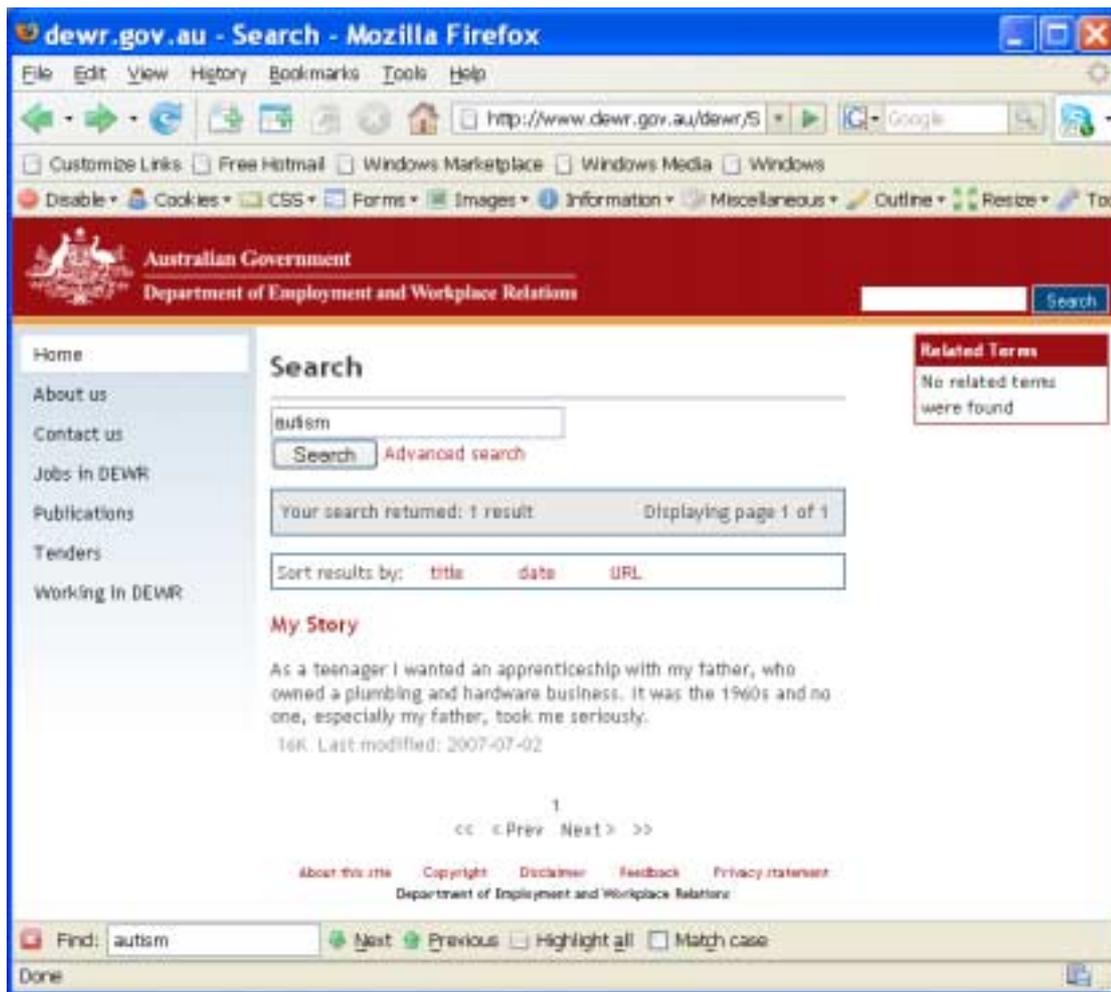
Alan Jones took up Jasmine Smith's story on *Paying the price of parenting an autistic child* (see elsewhere in this edition) on national television. Follow the link [http://www.2gb.com/index.php?option=com\\_content&task=view&id=2543&Itemid=163](http://www.2gb.com/index.php?option=com_content&task=view&id=2543&Itemid=163) for his comment.

## ***Inclusion, employment and DEWR's website***

Over the last 15 years or so, we have seen rapidly increasing numbers of children diagnosed with autism spectrum disorders. Australian governments, both state and federal, choose not to provide effective or evidence-based treatment, rehabilitation and/or education for most children diagnosed with autism spectrum disorders.

Children with ASD grow older — eventually they become adults. Now there are rapidly expanding numbers of young adults diagnosed with ASD needing some form of post-school option. For many, some form of employment would be desirable.

When I wrote to the Prime Minister last December, the Department of Employment and Workplace Relations (DEWR) website was not working. Recently, I returned to the DEWR website where a search for “autism” found just 1 result ...



This solitary reference to “autism” on the DEWR website (see <http://www.workplace.gov.au/workplace/Individual/Jobseeker/Careers/CareerJobSearchTips/All/MyStory.htm>) tells the story of a woman who encountered autism before she studied social work ... I do not regard it as informative about autism.

I repeated the experiment with each of “asperger”, “pdd” and “developmental delay”. The result was no links at all.

Searching the DEWR website for “disability” finds 802 hits. For example, it finds a link to DEWR’s Disability Support Pension Employment Pilot (see <http://www.workplace.gov.au/workplace/Individual/DisadvantagedJobseekers/DisabilitySupportPensionEmploymentPilot.htm>). This scheme is described thus ...

This pilot targeted DSP recipients who are able to be assisted by Job Network – primarily those who did not have significant ongoing support needs – who were not already participating in a form of Commonwealth assistance.

I would be interested to know how many people receive the Disability Support Pension who have *insignificant support needs*; that is how many people meet this criterion.

My real interest is with schemes for people with ASD who have significant (usually ongoing) support needs. Does DEWR have schemes for this group ... or are they in the process of developing such schemes?

Searching the DEWR website for “disability” and “significant support” seems to search for three separate words ... and finds 217 results. The page on “Disadvantaged job seekers” mentions:

- [Disability Employment Network](#)  
Information about specialist employment services for people with disabilities.
- [Job Placement, Employment and Training](#)  
Information about programmes to help young disadvantaged job seekers.
- [Personal Support Programme](#)  
This section has information about employment services for people who face significant barriers to employment.
- [PM's Employer of the Year Awards](#)  
Nominate the employer of the year.
- [Vocational Rehabilitation Services](#)  
Vocational Rehabilitation Services assist people who have an injury, disability or health condition to work independently in the open labour market.

Clearly none of these schemes has an autism-specific component (otherwise the previous search would have found it).

Experience shows that unless these schemes recognise and address the specific needs of people with autism spectrum disorders (especially untreated autism), they will not succeed for the rapidly growing number of people diagnosed with autism or ASD who are now becoming adults with autism/ASD.

We know from experience overseas that the Inclusion mantra/dogma is not a formula for success in education for students with ASD. Governments do not provide the resources required, and schools do not have the skills needed, to include students with ASD successfully in mainstream education settings.

A major problem arises when people see “Inclusion” just as a goal. They measure success by whether students with ASD attend mainstream schools.

The problem is that, while some student with ASD can attend mainstream schools, those students may not learn skills needed to function (either with or without support) in a workplace after they leave school. Inclusion has not been shown to be an effective approach to education that prepares students with autism for jobs, and especially for competitive selection processes. The success of Inclusive Education for students with ASD, in terms of employment outcomes, has not been demonstrated.

Governments and educators in Australia have yet to recognise or admit their limited achievement with inclusive practice in education settings. So far, the data does not show that including students with ASD in mainstream education settings leads subsequently to those students being included in a workplace ... or otherwise included in their community.

The Australian community needs to realise that their governments' hopes of extending this grand social experiment into employment and the workplace have little chance of success.

The government's current advertising showing modified workplaces, flexible working hour, etc. do not address the needs of people with ASD who want to work but cannot get the jobs that suit them or the support they need in a workplace. People could interpret this as the government's poor understanding of the needs of people with ASD.

It is my opinion that the Federal Government should develop employment programs that cater for the growing number of young adults with an untreated autism spectrum disorder who have recently left school, are now leaving school or will leave school in coming years. They need to recognise that existing policy and programs do not meet the needs of its citizens.

## ***On full-time caring***

The DEWR website refers to "Payments and allowances for people with disability, families and carers" (see <http://www.workplace.gov.au/workplace/Individual/Jobseeker/Support/Benefits/Paymentsandallowancesforpeoplewithdisabilitiesfamiliesandcarers.htm> ). One of these is Carer Payment (see [http://www.facs.gov.au/internet/facsinternet.nsf/disabilities/carers-carer\\_payment.htm](http://www.facs.gov.au/internet/facsinternet.nsf/disabilities/carers-carer_payment.htm)) on the FaCSIA website.

FaCSIA's website says people who provide "full-time care to an adult who has a disability or medical condition which is long term and severe..." can receive Carer Payment. Consider the use of the term "full-time" and what it means.

Centrelink decides who gets Carer Payment, so we need to see their eligibility requirements. Centrelink uses different language: their website (see <http://www.centrelink.gov.au/internet/internet.nsf/ea3b9a1335df87bcca2569890008040e/1884a0f18fee47ffca2572d6000ed897!OpenDocument>) says "you may get Carer Payment (adult) if you provide constant care in the home".

"Constant care in the home" seems especially restrictive. Hopefully this does not mean the government disallows Carer Payment if people with a disability and their carers leave their home or participate in their community. That would be contrary to various governments' "inclusion" policies.

Some new perspectives arise from the idea of "full-time care" meaning "constant care". For example, many politicians work longer hours in their jobs than most people I know ... but politicians and bureaucrats still do not work the extended hours that family carers work.

Still, it might be disrespectful to say that our country is run by a bunch of part-time politicians and administrators.

Despite their claims to the contrary, our governments are not respectful and/or appreciative of many people who provide enormous amounts of care for people with a disability. The government does not recognise the people who have a job and care for someone the rest of the time. These people work as carers for over 100 hours per week; but governments do not regard them as "constant" or "full-time" carers. The government's policy makes these carers ineligible for Carer Payment or any tangible expression of its appreciation and/or respect.

## ***At Parliament House***

There were two meetings at Parliament House last month. First I met with Senators Brett Mason and Gary Humphries from the Government.

Senator Mason is the latest Parliamentary Secretary for Health ... replacing Christopher Pyne MP in the role. You may recall that Senator Mason responded to concerns I raised previously about the Medicare item for people with sensory issues and communication difficulties being restricted to people with an intellectual disability.

Senator Humphries, the Liberal Senator for the ACT, helped me get the meeting. He started the meeting with a reminder of A4's Autism Awareness Event back in September 2004 (see the link <http://www.a4.org.au/awarenessevent/index.htm> for a reminder). Clearly this event created a strong impression. He pointed out that the Government has done nothing since to improve services for people with ASD, or the outcomes people with ASD experience.

While our meeting was set up around the Medicare item, the subject quickly became the "gap" or "abyss" in responsibilities that ASD falls into.

Senator Mason asked the head of the mental health section in the Health Department about service provision. She started out declaring that autism is not a mental illness/disorder.

I pointed out, immediately and fairly forcefully, that since 1994 PDD (or ASD) has been on Axis I in the DSM-IV, the same category as anxiety, depression, bi-polar disorder, schizophrenia, etc. There is no basis for bureaucratic saying that ASD is not a mental disorder<sup>1</sup>.

If ASD does not belong in the mental health category, where does it belong? Current treatment for ASD does not really fit with neurology or genetic conditions. Surely, it does not belong in oncology, cardiology, orthopaedics, etc. I cannot see mainstream medicine including ASD in immunology or gastroenterology. The Health system would continue its neglect of ASD treatment if it is left in its own distinct category.

I recall I had this same discussion with Health officials in Mr Pyne's office on two previous occasions. Clearly senior staff in Health oppose any Government recognition of ASD as a clinical disorder because this would mean the Department has responsibility for ensuring people with ASD get the clinical treatment and rehabilitation they need. The Department does not want that responsibility.

I referred to the advice about treatment contained in the Prior and Robert's report released earlier this year. The head of mental health said this is advice to the Department and does not reflect the Department's view.

The head of mental health said she is not a clinician, but she got her advice from clinicians. So senior bureaucrats in the Health Department depend on advice from mental health clinicians who say ASD is not a mental illness; that is advice from clinicians who spent their entire careers not treating ASD, and who have no clinical knowledge or experience of ASD. Most professionals would regard this as meaning they were unqualified to provide advice on treating ASD ... but apparently in relation to ASD senior Health bureaucrats have a high regard for complete ignorance; and they continue to use it as a their basis for denying people with ASD the clinical services they need.



In my view it is essential that the Government recognise many people with ASD have significant clinical needs, and that the Government is responsible for ensuring their clinical needs are met. Clearly the Government needs to show strong leadership on this issue.

Deciding that ASD is a type of mental illness is only a first step. It does not provide mental health professionals, GPs and workers in other part of the existing health system with the

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<sup>1</sup> I am aware that some members want to avoid the stigma associated with mental illness. But separation creates a stigma just for autism/ASD. I suggest we would do better to benefit from the progress made on reducing the stigma of mental health.

skills to address the clinical needs of people with autism. The decades of deliberate neglect of crucial services has to be overcome.

I raised the issue of the lack of response to my letter to the Prime Minister in December.

Hopefully, I conveyed the message that I am extremely disappointed by the Government's lack of progress. And that I am not alone in this regard.

The meeting ended with the Senators deciding to seek from the Prime Minister's Department a response to my letter to the Prime Minister, and clarification of responsibility for, and subsequent action on, providing clinical services for people with ASD from the Prime Minister's Department.

Do these Senators have enough clout in the Government to make something happen? I await the outcome.

Next, I met with Senator McLucas, shadow minister for Disability. You may recall in the last Update I had asked that she put a number of Questions on Notice to the Government. Her office wrote to me that the questions did not comply with Senate requirements. She asked a few questions of her own. But Senator Allison asked the questions exactly given, so clearly the form of the questions I suggested was not the issue.

When we met, Senator McLucas explained that she was not comfortable asking those questions. She needs to ask questions she is comfortable with.

I explained my disappointment that people with ASD who do not have an intellectual disability are excluded from the new Medicare item (see Correspondence: new Medicare item in Update #3, 2007).

I explained that ASD is a distinct disability, that the AIHW reports that ASD has the highest level of severe and profound disability, that the number of people with ASD is growing faster than other types of disability and that services needs have never been met. My arguments, including that most other disability groups are already represented in Government advisory bodies, etc. did not convince her.

She said there are lots of disability types and they all want their individual needs met. The position she took left me convinced that the ALP's policy is to treat all disabilities the same ... a policy that puts people with ASD at significant disadvantage relative to other disability types because of the historical neglect of ASD-specific services especially in the health sector and the recent rapid growth in number. She did not recognise that other disability groups have their specific needs met: for example, intellectual disability as mentioned above, vision impairment is specifically mentioned in the CSTDA, mobility issues are catered for, etc.

I raised the issue with her that there is no process in Australia to protect the human rights of children with ASD. We discussed the current situation wherein the Australian Government even dismisses adverse findings made against it by the United Nations Human Rights Commission.

I mentioned that the last Budget did not support people with a disability. And I expressed concern over how few disability-related media releases her website showed on the subject.

She agreed she would receive any proposals we sent her. The issue is whether she or the ALP would do anything with proposals it receives from the ASD community. In any case, we need to keep sending suggestions.

All of us need to contact candidates for the coming federal election and raise our concerns about the lack or inadequacy of services for people with ASD. It is up to us to ensure candidates in our electorate are very aware that people in the ASD community are unhappy. We need the issue raised routinely in both the Liberal party-room and the ALP caucus. Nor will we forget the smaller parties.

Please, please, please find time to do your bit. In the coming months A4 will provide you with suggestions as to what you can do. And don't just depend on A4. Please feel free to do your

own thing ... and write to the A4 Update editor with your own suggestions as to how to raise political awareness of ASD and the need for better outcomes.

## ***Human Right for children with autism***

The article *Tribunal decides no treatment for autistic children* in Update #2, 2007 describes serious human rights violations relating to discrimination matters affecting children with autism. The decision in seven matters, with annotations, can be downloaded from <http://www.a4.org.au/documents/ACTDiscTrib070425annotated.doc> (try this link if you could not get the document from the link given previously).

Information about this matter was distributed to a wide range of possibly interested and relevant groups and individuals. So far, none of them has responded or shown an active interest in the rights of young Australian children who are severely affected by autism. While Australian human rights and legal groups seem keen to protect the rights of possible refugees and terrorists, they show no discernible interest in defending and protecting the rights of Australia's most vulnerable citizens.

The apparent lack of a credible process to protect the human rights of people with ASD at either the state or federal level is now a serious personal concern of mine.

If you or someone you know is interested in action intended to protect the human rights for children with ASD, please contact me, preferably by email (see the contact information at the end of this Update).

Regards  
Bob Buckley



## **New Senator speaks out for disabled**

Queensland's newest Senator Sue Boyce has used her maiden speech in Federal Parliament to highlight the needs of people with disabilities.

The Liberal Senator has spoken about her experience as a parent of a child with Down's syndrome and says the Federal Government should avoid pumping money into large service organisations.

Senator Boyce says people with disabilities belong in the wider community.

"Anytime we allow people with a disability to be treated as special people who should live or learn or work or spend their leisure time in special places, we are shutting people with a disability out of the mainstream," she said.

"That makes vulnerable people more vulnerable to abuse and exploitation."

## **Using a Robot to Teach Human Social Skills**

Wired - Emmet Cole  07.09.07

Children with autism are often described as robotic: They are emotionless. They engage in obsessive, repetitive behavior and have trouble communicating and socializing.

Now, a humanoid robot designed to teach autistic children social skills has begun testing in British schools.

Known as KASPAR (Kinesics and Synchronisation in Personal Assistant Robotics), the \$4.33 million bot smiles, simulates surprise and sadness, gesticulates and, the researchers hope, will encourage social interaction amongst autistic children.

Developed as part of the pan-European IROMEC (Interactive Robotic Social Mediators as Companions ) project, KASPAR has two "eyes" fitted with video cameras and a mouth that can open and smile.

Children with autism have difficulty understanding and interpreting people's facial expressions and body language, says Dr. Ben Robins, a senior research fellow at the University of Hertfordshire's Adaptive Systems Research Group, who leads the multi-national team behind KASPAR.

"Human interaction can be very subtle, with even the smallest eyebrow raise, for example, having different meanings in different contexts," Robins said. "It is thought that autistic children cut themselves off from interacting with other humans because, for them, this is too much information and it is too confusing for them to understand."

With this in mind, the team designed KASPAR to express emotion consistently and with the minimum of complexity.

KASPAR's face is made of silicon-rubber supported on an aluminum frame. Eight degrees of freedom in the head and neck and six in the arms and hands enable movement.

The researchers hope that the end result is a human-like robot that can act as a "social mediator" for autistic children, a steppingstone to improved social interaction with other children and adults.

"KASPAR provides autistic children with reliability and predictability. Since there are no surprises, they feel safe and secure," Robins said, adding that the purpose is not to replace human interaction and contact but to enhance it.

Robins has already tested some imitation and turn-taking games with the children and his preliminary findings are positive.

"When I first started testing, the children treated me like a fly on the wall," he said. "But each one of them, in their own time, started to open themselves up to me. One child in particular, after weeks on end of ignoring me, came and sat in my lap and then took my hand and brought me to the robot, to share the experience of KASPAR with me."

Using robots to interact with children is nothing new, although there's been a lot of new research lately into this kind of work. The Robota dolls, a series of mini humanoid bots developed as part of the AURORA project, have been in use as educational toys since 1997.

The Social Robotics Lab at Yale is collaborating with a robotics team from the university's department of computer science to develop Nico, a humanoid robot designed to detect vulnerabilities for autism in the first year of life.

Relying on a robot to teach human social skills might seem counterintuitive, but autism presents a special case, said Dr. Cathy Pratt, director of the Indiana Resource Center for Autism at Indiana University.

"Autistic kids often interact better with inanimate objects than with other people, so a project like this makes sense and might lead to a safe way for these kids to learn social skills," she said.

However, autistic children often don't make the connection between what they have learned in a training situation and the outside world, said Dr. Gary Mesibov, a professor of psychiatry at the University of North Carolina and editor of the Journal of Autism and Developmental Disorders.

"I think this project will still be worthwhile, even if the children don't fully generalize what they have learned to the real world," Mesibov said. "But the key question facing the

researchers is whether the autistic children will be able to apply what they have learned from KASPAR in different situations and contexts."

Face recognition and emotion processing is a major area of deficit for autistic children and hampers their social development, said Dr. Jennifer Pinto-Martin, director of the Center for Autism and Developmental Disabilities Research and Epidemiology at the University of Pennsylvania.

Although autistic children often respond well to training, the process can be very labor intensive and the quality of the trainer is paramount, Pinto-Martin said. "People who work in this area need more creative ways to train around the deficits of autism. The quality and consistency of the trainer can be hard to control, but that's not the case with a robot.

"There is interactive computer software and video out there for testing and interaction, but the idea of using a robot trainer like KASPAR is a creative and wonderful step beyond current technologies and techniques," she said.

The project is due to end in October 2009.

## Autistic Care Wanting

[http://canberra.yourguide.com.au/detail.asp?story\\_id=1018280](http://canberra.yourguide.com.au/detail.asp?story_id=1018280)

Emily Sherlock

A man who failed to show the ACT Government had discriminated against his autistic son says many autistic children are missing out on key clinical treatments and early-intervention services in Canberra.

Bob Buckley, of Ainslie, says intervention such as applied behavioural analysis is not widely available or funded by the ACT Government.

The lack of early-intervention treatment formed the basis of a complaint by Mr Buckley to the ACT Discrimination Tribunal in 2000.

However, after more than seven years, the tribunal has ruled in favour of the ACT Government.

Mr Buckley says the claim failed owing to a loophole in the ACT Discrimination Act where Section 27 specifically protects the Government from claims of discrimination.

Now he is campaigning to see it changed and has written to several Government MLAs as well as the Prime Minister on the matter.

Also the ACT convener of Autism, Aspergers Advocacy Australia, Mr Buckley estimated there were 320 local children with autism spectrum disorders.

Last week he also took his concerns about the lack of autism services to ACT Minister for Disability and Community Services Katy Gallagher.

"What I would really like to see is the real treatment and rehabilitation clinical intervention introduced, which is something we have never had," he said.

"...teachers are expected to deliver clinical services in the classroom we don't do this to any other medical condition we don't expect teachers to be doing paediatric cardiology or cancer treatments in the classroom."

Ms Gallagher told the Sunday Canberra Times she noted Mr Buckley's concerns and "welcomed the opportunity" to work with him to deliver better autism services.

"Part of my job is to listen to what he has said ... and try to look at what we can do and importantly for his son what we can do to support his future goals and aspirations," she said.

"He has a view that he wants specialised clinical autism treatment and he argues that is not available through the health system in the ACT or through therapy.

"He is a very knowledgeable man around this but I believe that there are some people who work in the system who don't agree with this."

A spokesman for ACT Attorney-General Simon Corbell said the Government was not looking at changing the ACT Discrimination Act.

"Mr Buckley went to the independent discrimination tribunal and was not happy with the decision it found," he said.

Mr Buckley said his next port of call was to look into approaching the federal Human Rights and Equal Opportunities Commission to take the matter further.

## **CSTDA Briefing Note**

From the NDS website (<http://www.nds.org.au/national/default.htm>) *formerly Acrod*

### **26 June 2007 CSTDA Briefing Note to inform politicians and media**

NDS's briefing note on the CSTDA is now available on the [NDS website](#). An earlier version was distributed to Federal parliamentarians at the CSTDA breakfast hosted by the Parliamentary Friends of Disability, at which Ken Baker spoke. The briefing note will be updated as developments occur.

The [CSTDA briefing](#) is the first of several to be issued in coming weeks to inform politicians, journalists and other interested parties about key issues facing disability services in Australia. [Click here to read more...](#)

## **States stalling on disability services**

Federal Disability Minister Mal Brough has accused the states of stalling when it comes to providing services to disabled Australians.

In April, the state and territory disability ministers walked out of a meeting with Mr Brough after failing to reach an agreement on a Disability Funding Agreement.

Mr Brough has told Federal Parliament he gave the states an early June deadline to respond and he is still waiting.

"As of today, not one state and only one territory, being the ACT, has responded," he said.

"This is not good enough on the part of the disabled.

"The Howard Government will stand by these people and we would ask those who sit opposite to call on their state colleagues to start doing something positive about meeting the unmet need of our disability groups in Australia."

<http://www.smh.com.au/news/heckler/paying-the-price-of-parenting-an-autistic-child/2007/06/07/1181089237558.html>

## **Government Support for National Autism Symposium**

Community groups welcome the Australian government consideration of funding a national autism symposium.

Senator Bill Heffernan, in a recent letter indicated that he had approached the Minister for Health and Ageing the Hon Tony Abbott about funding a national autism symposium.

The national autism symposium will be the first fundamental step for government, non-government agencies and autism researchers to develop a strategic coordinated plan to address rising numbers of children diagnosed with autism in Australia.

Bob Buckley, Convenor of Autism Asperger's Advocacy Australia (A4), said "We welcome moves, developed in consultation with people with autism spectrum disorders and their families, that strengthen support and improve outcomes for these people. Over the last decade, the number of children diagnosed with an autism spectrum disorder has risen to at least 1 in 160 children. Autism is a life-long condition. A recent study estimated autism costs the nation around \$7 billion per year. Australia needs to invest in researching the causes of autism, effective treatment and how best to support people who have it. Research will lead to better outcomes for the whole community."

Associate Professor Deb Keen from Griffith University said "The Australian Autism Research Alliance (AARA) supports the call for a national autism symposium. The symposium would join together local and international researchers in their efforts to diagnose and treat this most serious disorder".

## Social Security Act

Below is a link to the Social Security Act including the Impairment Tables in the Schedules - schedule 1B

[http://www.facsia.gov.au/guides\\_acts/homeint.html](http://www.facsia.gov.au/guides_acts/homeint.html)

Chapter 2.3 Section 94. Qualification for disability support pension-continuing inability to work

[http://www.facsia.gov.au/guides\\_acts/sslaw/ssa/b819822a.html](http://www.facsia.gov.au/guides_acts/sslaw/ssa/b819822a.html)

Impairment Tables

[http://www.facsia.gov.au/guides\\_acts/sslaw/ssa/ssa\\_sched.html](http://www.facsia.gov.au/guides_acts/sslaw/ssa/ssa_sched.html)

## Book Review

### All Cats Have Asperger's Syndrome - Kathy Hoopmann

Jessica Kingsley Publishing ISBN 9781843104810

At first glance this book appears to be written for children but from my stand point it appeals to all ages. My 18 year old who has AS came home and said "HEY I read this great book on Asperger's." He said, "The phrases are simple, yet poignant, it is a very accurate portrayal of the syndrome, not full of myths, it is a positive slant on the differences that can be encountered by people on the spectrum. Although it is a short story the conclusion will leave you with the warm and fuzzies". This from someone with Asperger's is high praise indeed.

This warm and entertaining book is not only useful for those first discovering the autism spectrum for themselves, but those who want to share this information gently with relatives, teachers, classmates and others. The photographs are universally appealing.

Dr Tony Attwood, author of *Asperger's Syndrome* and *The Complete Guide to Asperger's Syndrome* says of this book: "The one thing I notice most about cats, and respect them for, is their independence. It's a funny thing because this is also what I notice about my Aspie friends. In fact, I see this in my own life as well. It's a unique quality that sets us apart from most other humans, just like cats are not like dogs. I mean we wouldn't want them to be, would we? Kathy's humorous book that highlights the unique qualities of individuals with Asperger's has us 'down to a T'".

Touching, humorous and insightful, this book evokes the difficulties and joys of raising a child who is different and leaves the reader with a sense of the dignity, individuality, and potential of people with AS. This engaging book is an ideal, gentle introduction to the world of AS.

Review by Joel & Vicki McKay

# Conferences and Workshops

ABA Conference Sydney August 12<sup>th</sup> - 14<sup>th</sup>

<http://www.abainternational.org/sydney/convreg/find.asp>

## 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.

**Update team:** [editor-at-a4.org.au](mailto:editor-at-a4.org.au)

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