UPDATE

A4 Autism Aspergers Advocacy Australia

August 2005
Issue 7

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HREOC National Inquiry on Employment and Disability

The Acting Disability Discrimination Commissioner, Dr Sev Ozdowski OAM, wrote to tell us he released the Interim Report of the Human Rights and Equal Opportunity Commission's National Inquiry into Employment and Disability. The purpose of the Interim Report is to:

(a) summarise the concerns and suggestions contained in the submissions made to the Inquiry to date;

(b) make Interim Recommendations on the basis of those submissions;

(c) propose a platform for action in the remaining months of the Inquiry.

The Executive Summary, Interim Recommendations and Next Steps for the Inquiry have been collated into Issues Paper 6 (Interim Report). You can find a copy of that Issues Paper at http://www.humanrights.gov.au/disability_rights/employment_inquiry/docs/Issue6_Interim_Report.doc. A full copy of the report can be downloaded from http://www.humanrights.gov.au/disability_rights/employment_inquiry/index.htm.

Both A4 and HREOC would like to hear members' opinions on whether HREOC's Interim Report addresses their issues and concerns in relation to employment for people with ASD. If you are concerned about employment for a person or people with ASD, please take a look at the report. Please let A4 know what you think; and if you can, write directly to HREOC as well. It is OK to say nice things, too.

Submissions to the Inquiry can be downloaded from the Inquiry website. The following table shows the submissions that mention ASD. Submissions 13, 112 and 129 are about ASD ... the others just make passing reference to ASD.

Sub. No.	Autism	ASD	Asperger	Description
13	Yes		Yes	Phillip Gluyas This submission describes personal experiences of an individual with AS. It shows an attempt to use the legal system to address issues in the workplace had quite adverse outcomes for a person with ASD.
23			Yes	Exton
36	Yes			ACTCOSS (ACT branch of ACOSS)
68	Yes			ACE
73	Yes			RDLO
87		Yes	Yes	Welfare Rights Centre Inc. (Queensland)
99	Yes			City of Darebin Disability Working Party, Vic.
112	Yes	Yes	Yes	Autism Aspergers Advocacy Australia (A4)
129	Yes		Yes	Anonymous

The Interim Report is disappointing as HREOC has not recognised our concerns.

Convenor's message

Dear A4 member,

I'm sorry the following message is rather formal and technical. I apologise for not contributing much that is fun and lighter to this edition.

After writing to Mr Abbott MP about not having seen any outcome from the Nations Autism Forum, I received an email on the 5 August 2005 from an official in the Health Department saying …

> *"… the Report of the Forum will be available shortly. It took some time to allow all of the presenters to confirm that they were happy with the way their presentations were summarised in the report. I regret this delay but felt that it was important to ensure that the content was accurate."*

The Health Priorities and Suicide Prevention Section in the federal Health Department is headed by a new Assistant Secretary. I was invited to a meeting very soon after he started in the position. We met on the 12th August and discussed a wide range of ASD issues across the spectrum and age ranges. We talked about the role of federal health and what responsibilities it might have in relation to ASD.

We talked about the spectrum … and I tried to explain that such a spectrum requires a spectrum of treatment and support options. I explained that ASD is a clinical diagnosis that by definition requires some clinical attention. Children who are diagnosed with ASD usually need early intervention that gives them social & learning skills and effective access to education. We discussed cost issues relating to ASD, both financial and non-financial, for the community and its various parts. I explained that the 'Commonwealth States and Territories Disability Agreement' specifically excludes the funding of clinical services; meaning FaCS and the disability sector do not accept responsibility for the clinical services people with ASD need. I pointed out that the mental health system regards those with ASD as "developmentally disabled", claiming their ASD cannot be treated. In this manner, the states' and territories' health systems deny people with ASD essential clinical intervention for their clinical disorder. I asked that they consider carefully their sources of information; especially whether it is appropriate to get their information from health professionals who have never treated ASD (or even reviewed the relevant research) and who continue to deny people with ASD access to clinical services (often based on the outdated belief that PDD/ASD is on Axis II in the DSM-IV, as it was in the DSM-III[1]).

We discussed ASD prevalence. And the creation of Cooperative Research Centres (CRCs) in ASD in both USA and the UK in response to the level of ASD diagnosis now observed. The

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[1] These are technical matters. Parents of children should not need to explain these technical issues to professionals … so please do not be concerned if as a parent you have no interest in or understanding of these issues.

influence of CRCs should extend well beyond research — they can give impetus to the training of specialist professional staff in areas of treatment and support. CRCs could monitor and report on outcomes.

They said the report from the forum is awaiting release from Christopher Pyne's office. Hopefully it will be released soon.

The last A4 Update showed Professor Bruce Tonge receives a large proportion of the NHMRC research funding given for research relating to ASD. Some of you may have heard Norman Swan's interview with Prof. Tonge in the Health Report on Radio National[2]. Norman Swan introduced the piece saying "Bruce Tonge and his colleagues have noted that the children's parents, perhaps unsurprisingly, have a higher risk of mental illness themselves. Much higher than parents of children with other disabilities."

In the interview Professor Tonge says "we had 120 families in this study, randomised into either a control group who got best standard early intervention" and "the treatment group, they had early intervention, best standard available in the area plus the parent education and skills training program".

Prof. Tonge is based at Monash University in Victoria. Few children in Victoria can access "best standard early intervention" in terms of access to specialised professionals and intensity of intervention. Numerous reports show that "best standard early intervention" is only available for a small number of children in Victoria whose families pay large amounts of money for services. If Prof. Tonge means Victorian state early intervention services when he says "best standard available in the area", then he is referring to services that fall well short of best practice. In the RHEF broadcast in March, Prof. Tonge endorsed a program in NSW that provided just 2 hours per week of intervention for the child.

The international consensus of professionals who specialise in effective early intervention and treatment of autism agree that the child should be able to access a minimum of 20 hours per week of individual program. State funded services in Australia, even at their very best, fall well short of best practice.

We are told stress increases the risk of mental illness. Not surprisingly, parents of children with under-treated autism, parents who are trying themselves to meet their child's intensive clinical needs and parents under significant financial stress due to their funding their child's intensive treatment … all experience higher than normal levels of stress. Increased mental illness among parents is the expected consequence of existing Australian practice.

Previously, research in Australia and overseas shows clearly that services providing best practice intervention for children without imposing a large financial burden on the family significantly reduces parent stress.

Tonge's research aims to reduce mental illness in parents. It seeks to do so either without addressing the needs of the child, or through somehow getting parents to meet the clinical needs of their child without increasing their risk of mental illness. Does this approach aim to achieve outcomes for children with autism equal to or better than existing best practice early intervention for children with autism? And how does Tonge's approach compare, in terms of parent mental health outcomes, to situations where children receive effective treatment for autism without causing major stress to parents?

Stress on families involving autism is well known. If you cannot access Prof. Tonge's program, you can consider a range of causes for your stress and a corresponding range of approaches to reducing your stress … such as those on the Autism Society of America website[3].

On the 11th August, I spoke on *The prevalence and incidence of Autism Spectrum Disorders in Australia* to the National Centre for Epidemiology and Population Health (NCEPH). There was a good size audience and real interest in the topic.

The message I gave NCEPH differs from the message Prof. Margot Prior gave to the National Autism Forum. You may recall from the June 2005 A4 Update #5 that Prof. Prior told the forum that just 1 in 1000 have ASD. My analysis is that Australian data shows 6 to 10 per 1,000 students will be diagnosed with ASD by the time they leave school. The Australian

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[2] 18 July 2005 … see http://www.abc.net.au/rn/talks/8.30/helthrpt/stories/s1417435.htm

[3] see http://www.autism-society.org/site/PageServer?pagename=livingfamily, http://www.autismsocietycanada.ca/life_with_asd_resources_families/support/index_e.html and many more.

diagnosis rate is similar to the best quality recent observations for the UK and the USA. The people at NCEPH, specialists in this type of measurement, did not raise any concerns about the analysis presented.

Prof. Prior is also mentioned in a recent edition of Journal of Paediatrics and Child Health (Volume 41 Issue 7 Page 391 - July 2005) over her editorial comments on a piece relating to autism treatment from Prof. Couper, an A4 member. Prof. Sven Eikeseth wrote …

> “Responding to Couper’s[4] proposal that intensive behavioural interventions (IBI) should be publicly funded and available to young children with autism, Prior[5] asserted that ‘… recent studies in Norway (S. Eikeseth, pers. comm., 2003) suggest that an intensive special education programme delivered by experts as part of normal educational provision for children with disabilities can do as well as traditional IBI’ (p. 506). However, these studies support the opposite conclusion.
>
> “Prior participated in a seminar on Autism in Oslo last fall, where I presented research that my colleagues and I are conducting in Norway. … The 1-year follow-up showed that, on average, children who received the behavioural treatment made significantly greater progress than those children receiving eclectic, special education treatment, though the two groups appeared similar at intake. … The results of [a] second follow-up show that children receiving behavioural treatment continued to increase their gains as compared to the children receiving eclectic treatment and that those children who received eclectic treatment had lost points on adaptive functioning.
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> …
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> “Thus, it is difficult to understand Prior's statements regarding our research. …

As parents, we need to be concerned about the quality of research in Australia and how research is reported to politicians and government decision makers. These issues significantly affect our lives and the lives of our children. We have a right to speak up on these subjects. Please have your say. It is crucial that a range of voices be heard on all issues.

Regards

Bob Buckley

The following article comes from United press International via the Schafer Report (edited version).

The Age of Autism: What epidemic?

By DAN OLMSTED

One of the core questions about autism is whether it actually has increased at startling rates or if it is just better recognized than it used to be.

Officials at the Centers for Disease Control and Prevention in Atlanta say they do not know the answer to that question but are trying to find out. Some medical experts say they think there really has been no upsurge in cases, just more public awareness and broader diagnostic criteria.

Don't tell that to many parents of autistic children -- parents such as Kendra Pettengill of Roseburg, Ore. She got in touch with UPI's Age of Autism to explain why she finds that argument not only ridiculous, but downright revolting. Because of the clarity and power of her comments, we decided to run them at length.

In future columns we will print observations by those who think there is no autism upsurge. If you agree, please get in touch.

Here are excerpts from Kendra Pettengill's comments:

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[4] Couper JJ. Who should pay for intensive behavioral intervention in autism? *J. Paediatr. Child Health* 2004; **40**: 559–61.

[5] Prior M. Intensive behavioural intervention in autism. *J. Paediatr. Child Health* 2004; **40**: 506–7.

If I hear one more reporter repeating the mantra that part of the autism increase is better diagnostics, I will simply go mad. Anyone who has seen even one child with autism knows that not one of these kids would ever go undiagnosed.

We would have to believe that 10 or 20 years ago a parent would not have demanded to know why their child had regressed after being normal. Would not have demanded to know why they suddenly couldn't relate to the outside world. Would not have demanded to know why they persistently rocked, flapped their hands, walked on their toes, bit themselves, pulled out their own hair and banged their heads to the point of serious damage. Would not have asked why their child had hundreds of meltdowns every day and could not stand a change in routine.

Would not have questioned why their child would not make eye contact, or screamed if they were touched or held. Would not have questioned why certain textures, foods, sounds, colors sent their children into a wild tailspin for no apparent reason. Would not have questioned why their child only ate three foods, but would chew on wood, sand, or fabrics. Would not question why their child could not speak at 2 years old, or why he could speak and then suddenly stopped abruptly never to speak again.

Parents, it would have to be believed, would not have questioned the litany of medical issues that their child with autism also faces. You would have to believe that schools and teachers also somehow missed all of this and these children managed school and just slipped through the cracks. To believe this you have never seen even a mildly autistic child.

No child with autism ever went undiagnosed.

I have been dealing with this for four years and I am still appalled that this has not been declared a national emergency. What if you announced tonight that 1 in every 150 children were being abducted from their beds every night? Parents would be screaming for the government, the police, somebody to do something. Well that is what is happening, except they are only taking our children's brains and leaving the body behind.

Many scientists, doctors, teachers and parents know that the increase is real and it is most likely due to an environmental assault such as vaccines. Denial using the "changed diagnostics" line serves no one. It leaves parents like me on the fringe of society, dealing with a devastating disease with no assistance. It abandons a generation of children that could be helped in many ways to become contributing members of society.

I beg anyone who believes it is better diagnostics to find all the 20-, 30-, 40-something people who have autism and were somehow missed in the process of life. They must be out there somewhere -- they went through 12 years of school, possibly college; married; got jobs, and were somehow missed as autistic.

Here is a hint. If they did all those things without being noticed by anyone, they are not autistic. This epidemic now is made up of kids who cannot do any of those things. They have no friends. For the most part they cannot even function in a typical classroom, let alone be missed in one. They can't comprehend classroom directions; hence even in a typical classroom they need an aide to ensure they gather the proper information and make it through their day.

Every teacher or school person I speak to says with utter fear in their eyes, "Something is very wrong with our children." We are being inundated with autism, ADD, ADHD, speech delays, tics, Tourette's syndrome, asthma, insulin-dependent diabetes.

I look back on my entire life, and I cannot come up with one single person I knew in grade school, junior high, high school, college, the Air Force or workplaces who exhibited what even I would easily recognize as even mild symptoms of autism, let alone a full-blown case.

There was a blind guy in my school who also rocked a lot, but so does Stevie Wonder. He also had no other symptoms of autism and even wrestled on the varsity team. You would think if it has always been this prevalent that I could recall at least one, if not many, people who would be questionable.

No, none. But then again, I didn't know anyone with asthma growing up, no children with ADD, ADHD, no kids or classmates with bipolar disorder or Tourette's either. Come to think of it, I never knew anyone on anti-psychotic medications, nor do I remember prescription cubbies in the classrooms like they have now to monitor and dispense all the inhalers, Ritalin, Risperdal and the like.

The teachers and educators and parents are right. What is wrong with our children that 1 in 6 has a developmental disorder, including speech delays, tics and autism on the severe end of that?

Those claiming better diagnosis instead of a real autism epidemic need to get out of their research clinics, get their noses out of their papers full of numbers that apply to no one in America, get out of their ivory towers, get out of their government offices and look in every small clinic, classroom and parent support group across America.

They will instantly know that not only is there an epidemic, it is actually 100 times worse than the worst-case scenario they could dream up in their worst nightmare. The denial of the numbers does not make them go away and cannot reduce them.

No child with autism has ever gone undiagnosed in any setting, in any decade, in any loving home, caring community or concerned school or classroom. Only in their unrealistic dream worlds can these "experts" continue to deny the millions of afflicted that continue to grow at record pace.

It is time this is stopped. Autism is an epidemic and a national crisis.

E-mail: dolmsted@upi.com

Letters / Emails

Hi Bob,

I would like to enter in into the ‘inclusion debate’. In the last update under National News you stated “The idealism of an inclusive society is as remote as ever. The ideological dogma of inclusion is at least as naive as communism”. I was extremely concerned about your comments as the article was not really about the inclusion of people in society but police brutality which is a totally different issue. Yes I believe that people who have autism are more vulnerable to police brutality and abuse, yes they should be protected from this unnecessary act, just the same as any other person in society, whether they have a disability or not. But to be able protect them, does that mean that we keep them locked up and away from society so that nobody can harm them? (We also know that research has shown that keeping people in secluded settings can sometimes facilitate opportunities for abuse – a major issue for institutions). Don’t people who have autism have the same rights as any other person to take their place in our society?

My understanding of A4 was to raise the profile of people who have a disability in a positive way and ensure that they receive timely and appropriate services – not to put one’s own prejudices of inclusion out for all to see. Isn’t inclusion about choice and shouldn’t A4 be promoting choice? Why isn’t A4 putting out the many positive stories about people who have autism that are living in the community and having a valued role?

I have attached an article which compares mainstream and special schools which I would appreciate you taking the time to read, especially page 9 – Inclusive Primary Schooling, I think that positive reports like this deserves a mention on the A4 Update.

I would be happy to discuss this further

Kind regards
Liz Blakey

Hello Bob,

I thought you might like to distribute the following link regarding the inaugural Asperger's Syndrome conference in Brisbane.

"Talking with us" is the first 3 Day National Conference including an ASD Services EXPO to be held at The Bardon Centre, Bardon, (Brisbane, Queensland) from Thursday 20 October to Saturday 22 October 2005.

During the 3 Day National Conference we will:

- hold workshops for people on the spectrum facilitated by people with ASD raise the profile of ASD
- provide vibrant forums where people with ASD are having a voice
- establish greater communication between ASD people and the wider community linking ASD into the community

Delegates from all over Australia, neighbouring countries and overseas are expected to come together over the 3 days for this first of its kind conference.

Delegates will include people on the Autism Spectrum, families and carers, professionals, academics, service providers (government and non-government) and members of the business community.

www.iamevents.com.au/asa

Kind Regards
Lionel

The following is a follow-up letter Caroline Cristina sent to Tony Abbott regarding the petitions.

The Honourable Tony Abbott MP
Minister for Health and Ageing
House of Representatives
Parliament House
Canberra ACT 2600

Dear Mr Abbott MP,

I am writing to congratulate you on holding the recent Autism Forum in Canberra and to thank you for pledging $50,000 toward autism research!

Thank you also for tabling my out of order petition of 704 signatures in the House of Representatives on 2nd June 2005. The petition asks for the establishment of a National Autism Registry and Voluntary DNA Database. I would like to know if you support the wishes of the signatories of this petition.

Could your government fund the establishment and maintenance of a National web-based registry of newly and already diagnosed Australians who have autism? At the Autism Forum, Dr. Angus Buchanan of the Western Australia's Disability Services Commission told the forum that the implementation and maintenance of their State's Autism Registry was not costly.

It would be wonderful if General and Specialist Practitioners could register each person on-line, including in their registration which of the five types of Autism, (as described in the Internationally recognised diagnostic tool, the Diagnostic and Statistical Manual of Mental Disorders), their patient had. This would make autism research consistent with the existing Cancer, Pap Smear and Immunization Registry initiatives.

When I initially consulted Professor Bruce Tonge of Monash University about the idea of a National Autism Registry and Voluntary DNA Database, he told me that either or both initiatives would be of outstanding assistance to the field of Autism Research and thus greatly assist the 1 in 100 Australian citizen affected by Autism. In fact, members at the latest meeting of the Autism Research Alliance Australasia reiterated the need to create and maintain a National Autism/ASD Register.

Yours sincerely
Caroline Cristina

Do you know a family in NSW, SA or QLD who has an infant (6-12 months old) or a child (4-5 years old) growing up in a family where either a sibling or a parent has a disability? If so, please refer to email below. This is an opportunity to be involved in a longitudinal study over a 7 year period. Applications close August 2005.

Please pass this information on to your colleagues, networks and families in NSW, SA & QLD – Thank you

See email below for further information.

Helen Johnson
Coordinator
Australian Association for Families of Children with Disability (AAFCD)
Ph/Fax: 1800 222 660
Email: helenj@aafcd.com.au
Web: www.aafcd.org.au

Dear Helen,

We are looking for a family where there is an infant (6-12 months old) or a child (4-5 years old) growing up in a family where there is a disability - either a sibling with a disability or a parent with a disability. We are targeting NSW, Southern Qld (Brisbane region) and South Australia (Adelaide region). It will involve short visits every 18 months over a seven year period to determine the development of selected children growing up with some in the family who has a disability.

Thanks for your assistance with this,

Kind regards,
Catherine.

Catherine Marciniak
Director - "Growing Up In Australia"
c/- Film Australia
PO Box 46, LINDFIELD. NSW. 2070.
Ph: (02) 9413 8745 Fax: (02) 9413 8780
Mobile: 0419 445731 Email: cathm@mullum.com.au

A4 Contacts

Update team (newsletter)
edit@a4.org.au

A4 Convenor, Bob Buckley
convenor@a4.org.au

Treasurer (donations)
treasurer@a4.org.au