UPDATE
A4 Autism Aspergers Advocacy Australia

August 2008
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online *Carers Summit*

Hello everyone

During the month of August, there will be an online *Carers Summit*, to find a 'big new idea' for carer and family issues, along the lines of the Rudd Government's 2020 Summit in April.

Please participate in this event. Click on the box below or go to http://www.carers2020.com.au/index.html to get there. You'll see that comments are invited on each section.

I have written one of the 5 pieces to start the discussion, on *Models of Care*. (The other 4 sections are rather dull, I think). Senator Helen Coonan also has a very good introduction on 'consumer-directed care' in her welcome.

This is a good opportunity to get some national debate going. So please contribute and push the debate along.

Regards
Vern Hughes
0425 722 890

June 11

Inside this Issue

Disclaimer

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Launch of PlayConnect Playgroups

Playgroup Australia will receive funding from the Australian Government to roll-out 150 playgroups for children with Autism Spectrum Disorders (ASDs) over the next four years.

Visiting a playgroup in the Brisbane suburb of New Farm, Parliamentary Secretary for Disabilities and Children's Services, Mr Bill Shorten, announced yesterday that playgroups for children with ASD were part of the Australian Government's $190 million Helping Children with Autism (HCWA) package.

By 30 June 2009, at least 50 PlayConnect Playgroups will have started. A further 100 PlayConnect Playgroups will start by 30 June 2011.

Playgroup Australia Executive Officer Karen Merange said that PlayConnect Playgroups would provide play opportunities for children with ASD and those with ASD-like symptoms.

"PlayConnect Playgroups will also link to other components of the Australian Government's Helping Children with Autism package of services.

"PlayConnect Playgroups are not offering therapy services, but what they are offering are safe and supportive environments for families to meet together where the focus is on assisting young children's optimal development and well-being through play," she said.

PlayConnect Playgroups will be open to participation by children both with and without a formal ASD diagnosis.

"By not requiring a medical diagnosis of ASD, children with ASD like symptoms will benefit by being able to participate in developmentally positive experiences at an earlier age. For parents, taking away the requirement for a formal diagnosis will ease pressure on them during what is often a stressful time.

"Being able to meet and connect with other families in similar situations will provide support during what is undoubtedly a difficult time. It's a great way for families to create a support network.

…

To read more, see http://www.facs.gov.au/internet/facsinternet.nsf/disabilities/services-asd_playgroup_program.htm and http://www.playgroupaustralia.com.au/go/news/launch-of-playconnect-playgroups

Convenor's message

Dear member,

We have cause for major celebration. The fantastic news is that the Government's *Helping Children with Autism* (HCWA) package is under way.

The first part of HCWA off the mark is the Health Department's Medicare items. Feedback so far is that people are unsure of how they can use these items. My son is too old to access these services … however, I understand that if your child already has a diagnosis you will need to ask your GP to refer your child to a paediatrician (or a child psychiatrist) who then refers your child for allied health services. You might first ask whether any allied health people in your region with sufficient knowledge, skill and experience of ASD have the capacity to see your child once you get a referral. I apologise that I do not know who to suggest you ask.

The pilot runs through teacher and parent training, federal Education's component of the HCWA package, were done recently. This part of the HCWA package is for the largest number of people with ASD. DEEWR's website[1] says this part of the package is for …

> Parents and carers of school aged children with ASD can participate in the workshops and information sessions. 'School aged' refers to children in a primary or secondary Australian school, in all school sectors and across all educational settings.

Notice the workshops are for families of **all** school age children with ASD. Look for more information at www.autismtraining.com.au, especially after mid-September.

The article (see *Launch of PlayConnect Playgroups*) above describes the playgroup element of the Government's HCWA package. People who are interested in getting their child into a playgroup can get more information from the website, or may soon be able to ask an Autism Advisor in their region for more information.

Applications for the Childhood Autism Advisors have closed. There are concerns about the independence, objectivity and expertise of the people who will fill these roles. A4 will let you know how to contact an Autism Advisor in your area as soon as possible.

Applications for listing on the Early Intervention provider panel closed on 18/8/2008 (see http://www.fahcsia.gov.au/panelapplicationpack). The Government will choose a panel of service providers for families of young children with ASD to get up to $6,000 of early intervention per year for two years.

The Government wants providers to get together in multidisciplinary teams to offer early intervention. I appreciate the Government's apparent intentions though it is not founded on evidence from research. The need for providers to join in teams challenges some of our existing service providers. Some established service providers told me they did/could not do it.

I will be surprised if initially there are enough service providers on the first panel to meet demand for early intervention. Meeting initial demands was always going to be a challenge. People in rural and remote settings may find they cannot access early intervention services on the panel.

I am disappointed that the Government wants service providers to meet just 10 of the 13 "best practice principles" listed in the Prior & Roberts brochure. The Government omitted three "best practice" principles from their panel selection requirements. I am especially concerned that they dropped the "intensity" principle. No doubt the 22,000+ people who registered in the 1000 Hours campaign hope that the Government will require best practice intensity as soon as it becomes practical.

Registrations of interest for the 6 Childcare Centres close on 29/8 and applications close 26/9 (see http://www.facs.gov.au/internet/facsinternet.nsf/ca4cf882aebb6ca7ca256d0

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[1] see http://www.dest.gov.au/sectors/school_education/programmes_funding/programme_categories/special_needs_disadvantage/helping_children_autism/default.htm

1001a08a7/9d0523ce9295fc7cca25748a00159d01?OpenDocument). Are there really enough young children with ASD in North West Tasmania to occupy an ASD-specific childcare centre on a fulltime basis?

While the new Labor Government has kicked off the HCWA package, recall that the HCWA package is just a start. The Government needs to do significantly more in order to deliver on Labor's autism-related election promises found at http://www.alp.org.au/media/1107/msedutfcshealoo160.php. Near the bottom of the page, they say …

> Federal Labor will also ensure there is a greater focus our children's healthy development through:
>
> - …
> - Comprehensive early intervention and specialised child care services for children with autism.

With the start of the Helping Children with Autism package, Mr Rudd's Government can claim "there is a greater focus our children's healthy development … for children with autism".

Most likely, the Early Intervention element of the HCWA package will contribute to "comprehensive early intervention" for some children aged up to 6 years who are diagnosed with ASD. Only a few existing service agencies provide Early Intervention meeting the 13 principles listed in the Government's Best Practice Guideline's document. It is unlikely the HCWA measures will significantly increase the number of children who receive early intervention at the standard described as best practice. The bulk of the cost burden for best practice early intervention will continue to rest on the families and relative few can meet the financial burden, even with an addition $6,000 per year.

I doubt families will accept the HCWA package delivers Labor's election promise to ensure "comprehensive early intervention" … since $6,000 per year is but a contribution towards this promise.

The Government is aware that $6,000 per annum is a relatively small contribution towards the annual cost of comprehensive early intervention for autism (as described in its best practice guidelines). Many children with autism need more flexible access to funding … like the funding that the ISS scheme and its Inclusion Support Program[2] (ISP) offer if the early intervention element of the HCWA package is to benefit them.

Recently, the ISS Scheme was transferred to DEEWR and apparently morphed into the Inclusion and Professional Support Program (IPSP). Some brief information is available on the web[3]. This scheme seems to have been largely refocussed on indigenous issues.

Despite the Government's claim on the website that

> The Inclusion Support Program (ISP) supports child care services so they can welcome and include all children, including those with additional needs.

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[2] See http://www.dest.gov.au/sectors/early_childhood/programmes_funding/inclusion_support_program_factsheet.htm

[3] See http://www.dest.gov.au/sectors/early_childhood/programmes_funding/child_care_inclusion_professional_support_program.htm

ISS funding[4] is not accessible for many children with ASD who need an intense ASD-specific program for their development of language, social skills and appropriate behaviour with professionally supervised support in a naturalistic/inclusive childcare setting.

And the Government's 6 specialised (ASD-specific) childcare centres will only deliver childcare for a limited and select group of children diagnosed with ASD. Again, it represents a greater focus on the needs of children with ASD but substantial unmet needs remain.

A4 members tell me they remain keen to see Labor realise its election promise to ensure "specialised child care services for children with autism".

Significant Federal/State cooperation over service provision for people with ASD has yet to emerge. This lack of cooperation represents another unrealised promise. The resultant need to access both state and federally funded service systems complicates the lives of people with ASD and their families unnecessarily. While the autism advisors may be able to help families face the complexities of the various systems, the complex and incomplete systems continue to be a feature of services for people with ASD.

Policy at state level remains a complete mess. My last message showed the Tasmanian Premier denigrates the massive efforts some families make on behalf of their children. Below, we see a Queensland Senator (see *MP calls for scrapping of special schools*) oblivious to the documented inability of mainstream schools to meet the needs of many students with ASD. Previous editions of A4's Updates contain a litany of failures in existing state systems.

I had better finish now so that I can send this out. Please let us know how the Federal Government's *Helping Children with Autism* package works out for you and those in your care.

Regards
Bob Buckley

24/8/2008

Students with autism in mainstream ...

The Government's website[5] offers a document entitled *Students with Disabilities in Mainstream Classrooms: A Resource for Teachers*. The document mentions "autism" 3 times and "Asperger" once. The first mention of "autism" says ...

> **What teachers do**
>
> Many teachers adopt creative ways of responding to students' difficult behaviour and try to understand what function the behaviour might serve for the student. One primary school teacher who has a student with autism in her class has set up a yurt in the classroom. The student – and others as well sometimes – go into the yurt for a short time if they feel they are going to lose control or have an outburst.

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[4] I suggest this is an example of disability discrimination that Australian law protects but is outlawed by international law (so much for the recent signing of the treaty on rights of people with a disability). In relation to our Government's position on China's human rights record, they should be careful as people who live in glass houses should not throw stuff.

[5] http://www.dest.gov.au/NR/rdonlyres/D3113371-7E2C-49FE-8017-8495030736BF/19755/InclusiveClassroomTeacherResourceFinal1.pdf

This “advice” is somewhat incomplete. The teacher needs to ensure the student will not learn to "escape" into the yurt to avoid learning and/or social challenges and the like.

How will this child go in high school? Does he drag his yurt around with him from class to class (and what do the other students who use the yurt do when they are in a different class) ... or does the high school put a yurt in each class for them? Just how many high school classrooms have room for a yurt?

How many primary school classrooms happen to have enough space for an extra yurt?

Schools should use strategies with students with ASD that are generally applicable through their student's life. Who wants a child to become dependent on having their yurt available to manage their behaviour?

Notice that because a teacher invented yurt-based behaviour management, and the inclusion gurus endorsed this approach, it is used as a showcase example. Perhaps we will see the invention of a string of new approaches to in-school behaviour management for students with ASD such as tee pee therapy, adobe accommodations, bivouacking, ... But when parents suggest such an approach, typically school staff ridicule them and barricade themselves behind a plethora of obstacles to using any such method.

The “resource” is inconsistent in relation to withdrawal. A core feature of yurt-based behaviour management seems to be that children withdraw before they "lose control". A child with ASD may need to practice "withdrawing before losing it". Being withdrawn is mentioned once in the whole document: it is portrayed negatively in relation to Michael on page 9 who "hates [being] withdrawn" (and is not described as having ASD). This section says "his academic performance was being held back by his behaviour and social skills" but focuses on curriculum seemingly with the expectation that this will solve his behaviour and social problems. But the evidence shows children with ASD need specific attention to their behaviour and social problems: the document fails to emphasise that their non-curriculum needs must be addressed.

In the inclusion model, withdrawal is a type of segregation, a complete no-no. So generalised withdrawing of a student is not acceptable in inclusive education ... unless the student can withdraw to a yurt that is included in the setting.

Detailed comments about the subsequent times autism is mentioned in the resource does not seem a worthwhile exercise.

Many students with a disability need expert clinical support for their education but they do not get it. The inclusion model particularly, and the education system generally, ignore the students' needs for specialist input to individual programs. The booklet does not mention psychology or psychologists (but it does mention speech pathologists ... once on page 19).

In the UK, a bastion of inclusive practices, the Parliamentary Committee on SEN was told in recent hearings that 25% of students with ASD are excluded from school at any one time. We have no measure of how many students with ASD in Australia are excluded from their school though anecdote would suggest at least as many students are excluded here.

A 40 page "resource for teachers" does not compensate for the chronic lack of expert input to students' individual programs and governments' failures to ensure students with ASD get the support they need in their education.

Governments, both state and federal, must appreciate that despite the best efforts of schools to meet the needs of students with ASD, they are not equipped to educate some children with ASD. Evidence from mainstream school principals shows ...

> There is a subtle disparity between the verbalised belief that their schools were inclusive and that all children were considered to belong – and the consistent reference to the critical need for comprehensive support from specialist teaching staff in order to manage the students with AS.

> See www.aase.edu.au/index2.php?option=com_docman&task=doc_view&gid=51&Itemid=97

The reality is that many students in Australia are routinely excluded from school. A school principal responsible for inclusion in a mainstream setting was reported as saying …

> *"I think sometimes people are frightened of these kids and they don't have the skills to deal with them, so it's a "I'll get rid of them for five days, or I'll get rid of them for twenty days" and then I don't have to deal with the issues".*

and

> *"The parents are just concerned about the children's safety, and you know if they saw the kid with the baseball bat they'd be worried about the other children's safety – and that's where my role is – to say well we would at all times keep your child safe, we would remove that child, the child that's got the baseball bat from the playground, or we would take their reward time from them. They can see that, it's highly visible that that's what we do, we take them out of the way, but you know these are little kids that have got to learn to socialise and they are going to go into the community and they are going to meet people who are going to get up their nose and they are going to feel angry, so they need to know what to do when they feel angry. We can't suspend them from society, so we've got to have other strategies."*

Unfortunately, generic special schools may not be better. Few state special schools provide the ASD-specific programs and support that students with ASD need. Rarely are specials schools considered an appropriate setting for students with Asperger's disorder (or high functioning autism). So increasingly, students with Asperger's disorder are sent to education setting that cater for students with "challenging behaviour". Unfortunately, it is rare that these settings are adequately equipped to address the needs of students with Asperger's disorder … again, they do not get the help they need which often leads to their exclusion, either socially or physically.

Until the health and education systems cooperate to prepare students and provide the clinical support that some of them need, schools simply cannot unilaterally include all students with ASD. The persistent refusal to recognise this basic fact is the foundation of ongoing failure.

Some of the outcomes are described in Thierry Bourhour's *The Journey of the Excluded: Schooling and Crime in the Exclusive Society*
(see http://www4.gu.edu.au:8080/adt-root/uploads/approved/adt-QGU20071112.093024/public/02Whole.pdf).

Disability benefits in Queensland

The **Carer Business Discount Card** is now available for carers. The scheme has been launched and is open to applications.

You can apply for a card at
http://www.communities.qld.gov.au/community/carerbusinessdiscountcard/

Two weeks to go for award nominations

The Disability Action Week Awards are an excellent way of highlighting the contributions that members of your community are making to improve the quality of life of people with a disability.

Help recognise these deserving Queenslanders by nominating them for an award.

You can also encourage other members of your local community to nominate an individual, community group or organisation for an award.

For nomination forms and further information visit
www.disability.qld.gov.au/actionweek/awards

A total of 13 Disability Action Week Awards will be presented to acknowledge the outstanding achievements of those who are making a difference for people with a disability.

Nominations close on 8 August 2008.

Winners will be announced on Tuesday 16 September.

Please distribute this message to your networks and contacts to help promote the awards.

Kind regards

Dianne Dizo
Principal Communications Advisor

Strategic Communication Services
Corporate Performance and Portfolio Services
Department of Communities | Disability Services Queensland

(T) 3235 9790 | (M) 0434 603 860 | (F) 3234 1874

National Carers Coalition
"Walk a Mile in Our Shoes"
Address All Correspondence to PO Box 937 MOE VIC 3825 - www.carers.net.au for state contacts

Carers Bulletin

We are planning to launch a national email and letter blitz upon our Government Ministers and our elected representatives who are failing in their commitment to support caring families and those for whom we care.

Campaign letters, postcards and news bulletins will be sent to you to invite you to join us again in

Walking Together to achieve a fair deal for family carers including, as a first priority, the funding for a regional, state and federal carer family advocacy network so that we too will have a voice in policy and planning.

Contained in this mail-out is a pro-forma letter to the Minister for Family and Community Services, Hon Jenny Macklin asking her to give us the funding for a regional, state and national family advocacy network. We ask you all to date and sign the letter, adding your address details and posting it to the Ministers Office in Canberra. We hope for thousands of these letters to be sent showing Minister Macklin and her government that carers do matter and we want our own voice to be heard.

If we can persuade you to also send a copy to your local Federal MP's, so much the better, state Governments and all our MP's have a responsibility to support us too don't they? As a group of unpaid accommodation and personal care providers we are now worth over $41billion to the economy. It is way past time for governments to meet their obligations to us, isn't it?

If you have a network of caring friends we invite you to pass this information on to them with an invitation to "Walk a Mile with us" by joining us. Ask them to send us their contact details, including clearly printed postal and/or email addresses for inclusion in the ongoing campaign.

To join the NCC is FREE, but we encourage carers to consider making a donation if they can, to help us pay for this campaign. A copy of this Bulletin and 'form letter' are attached to this email. A Membership application Form is also included.

Ask your local MP to make copies for you to hand out. Ask the service providers that help you and your loved ones to copy the package and send it home to all their client families.

State Liaisons in other states will also be assisting with this mail-out so you may receive info from NSW, QLD, WA, SA, TAS, etc, because we are all in this together as carers. Together we can all walk Miles in our Shoes and make a difference. It is time that we say we want our own Advocacy networks so that we can tell governments how best to help us do our irreplaceable job of caring.

If you do not wish to receive any more information from us, please indicate by return mail or email.

Yours sincerely,
Jean L Tops
Victorian Liaison Carer
National Carers Coalition
Phone: 0351271904
Mobile: 0402 650 375

An Australian Compact?

The Australian Government, as part of its social inclusion agenda, is exploring ways to develop a new and stronger relationship with the not-for-profit sector, based on partnership and respect.

One way to do this is through an Australian Compact-an agreement between the Australian Government and the not-for-profit sector that outlines how the two will work together to improve and strengthen their relationship, now and into the future.

For more information, see http://www.facs.gov.au/internet/facsinternet.nsf/communities/australian_compact.htm

Dear member, how should A4 respond to this request from the Government? If you have knowledge or experience of such a compact (for example, with a state government) A4 would be interested in your thoughts and feelings on this subject.

ABS Study

The Australian Bureau of Statistics released an article entitled Australian Social Trends 2008: Families with a young child with a disability (see http://www.ausstats.abs.gov.au/ausstats/subscriber.nsf/0/3763CFE209656C3BCA25748E00129716/$File/41020_2008_4.pdf). The article looks at disability generally: it does not separate children with ASD at any point).

The data suggests these families do not do well.

The AIHW has reported previously on this data (from the ABS 2003 Survey of Disability Ageing and Carers) in more detail.

In the news

MP calls for scrapping of special schools

The Courier Mail *By Renee Viellaris, June 23, 2008 04:18am*

QUEENSLAND Liberal Senator Sue Boyce has called for special schools to be scrapped and disabled children sent into mainstream education.

Senator Boyce, who has a daughter with Down syndrome, said it was time someone was "brave" and "crazy" enough to push for total integration of students.

"We won't fix education until we abolish special schools," Senator Boyce told a Down Syndrome Association of Queensland fundraiser last week.

"If mainstream schools had no option but to accept children with disabilities, they would concentrate on how to make it work, not how to avoid getting involved.

"And if all the human and funding resources currently tied up in special schools were handed over to the mainstream system, it would be so much easier to make it work."

…

read more at http://www.news.com.au/story/0,,23906504-2,00.html#

Ex-childcare worker admits to rubbing soiled nappy in boy's face

The Courier Mail Tony Keim, August 01, 2008 12:00am

A FORMER childcare worker has admitted in the Ipswich Magistrate's Court to rubbing a soiled nappy in the face of a mute, disabled boy in her care.

Cressy Ann Thomas, 28, made a brief appearance charged with assaulting a child at a Camira childcare centre, 25km southwest of Brisbane, on September 8, 2006.

Solicitor Luke Pearcy, for Thomas, said his client had hoped to resolve the matter through mediation.

However, he said police, acting for the disabled child, had rejected her request and demanded the matter proceed through the criminal courts.

Mr Pearcy entered a plea of guilty on behalf of Thomas, who stood next to him during the brief hearing.

read more at http://www.news.com.au/couriermail/story/0,23739,24108010-3102,00.html

Comment: This story reflects the difficulties that mainstream childcare centres have with children with autism. The centre in this matter may have received ISS funds of $16/hr of Commonwealth money to "include" the child … but without crucial training, professional program input and supervision.

Opinion: We can learn from special schools

Brian Caldwell, August 11, 2008

http://www.theage.com.au/education/opinion-we-can-learn-from-special-schools-20080809-3sm8.html?page=-1

JULIA Gillard has called for a "raging debate" about how our education system compares to the best in the world, how to ensure that every school is a great school, and how to ensure every child gets an excellent education.

Accepting Ms Gillard's challenge leads to ground-breaking conclusions in some fields. I believe that the education revolution will not succeed until all schools adopt some of the practices in the best special schools. Special schools serve students with moderate to severe disabilities. I'd like to highlight two practices: personalising learning and a focus on the arts.

Personalising learning has become a mantra in efforts around the world to secure success for all students. A common feature is that there is a learning plan for every student, progress is monitored frequently, support is available to get the student back on track should he or she fall behind, and at least one teacher knows the student well and serves as a mentor.

Millions of frequent-flyer points are being accumulated as educators fly to Finland to learn the secrets of its success. One factor stands out: each student is monitored so well that the moment he or she falls behind, special support is provided, either one-to-one or in small groups.

Why do we need to fly to Finland to fathom this out, when our best special schools are models of world-best practice? They have a personal learning plan for every student. They monitor progress on a daily basis. Staff work in teams to ensure that needs are diagnosed and action is taken.

At Port Phillip Specialist School, for example, the integrated services committee of school leaders, therapists, specialists and teachers meets weekly in a cycle that ensures the progress of each of its 150 students is discussed regularly and a course of action is planned. Parents may attend in some instances.

It's the same at the Western Autistic School, which serves 240 students with autism and Asperger Syndrome. These and similar schools also act as links to external agencies and service providers in their determination to ensure services are tailored to student need.

I see no difficulty scaling up to a school of 1500 students these approaches that are working so well in special schools of 150 students. It will mean remarkably different approaches to the delivery of services, with teachers and other professionals working in clinical teams in an educational counterpart to the best medical practice.

New skills are required, and this was recognised in Finland, where every teacher must now have a master's degree and those who provide individual and small-group assistance to students receive additional training and higher salaries.

In some instances, schools will set up their own training centres, as occurred at Western Autistic School, which established the Autism Teaching Institute, offering university-accredited programs that bring participants to the forefront of knowledge.

These strategies call for innovation in school management and creativity in building professional capacity. Meeting the additional costs will be a test of our resolve to secure success for all students in all settings. These commitments lie at the heart of the education revolution.

At a recent symposium on "Re-imagining Special Education", hosted by Port Phillip Specialist School, particular attention was given to the place of arts education and arts therapy in special education.

In Musicophilia: Tales of Music and the Brain, Oliver Sacks, Professor of Clinical Neurology at Columbia University, provides a powerful affirmation of the approach. He refers to those "who may be unable to perform fairly simple sequences involving perhaps four or five movements or procedures - but who can often do these tasks perfectly well if they set them to music. Music has the power to embed sequences and to do this when other forms of organisation (including verbal forms) fail". The power of music is demonstrated daily in the music therapy program at Port Phillip. Its work in art, drama and dance is equally inspirational.

What is central to success in special education should also be central to education in general. In Creators, Paul Johnson declares that "creativity is inherent in us all" and that "the art of creation comes closer than any other activity to serving as a sovereign remedy for the ills of existence".

It is therefore startling that there is no place for the arts in the current brief of the National Curriculum Board, which operates under the auspices of the Council of Australian Governments (COAG). Its task in the first instance is to develop a national K-12 curriculum in English, mathematics, the sciences and history. After that, it will work on geography and languages other than English. There is no reference to the arts.

Harvard University's Howard Gardner is one of the most influential people in shaping curriculum. In Five Minds for the Future, he argued that "it is essential" for all to think in ways that characterise the major disciplines. At the school level, he declares that "my own short list includes science, mathematics, history and at least one art form".

Including the arts in a national curriculum was proposed at the Australia 2020 Summit in the "Toward a Creative Australia" stream co-chaired by Cate Blanchett, Peter Garrett and Julianne Schultz.

The education revolution is stunted by the omission of the arts in the work of the National Curriculum Board. COAG should ensure that this is rectified.

Ms Gillard and Kevin Rudd have called for the engagement in education of business and philanthropy. This is a field in which some special schools excel. The Port Phillip Specialist School arts in education program is supported by 36 organisations and institutions, including some of Australia's largest companies and leading foundations and trusts.

In her recent John Button lecture, Ms Gillard referred to John Maynard Keynes, who said that "When the facts change, I change my mind. What do you do?"

I suggest that the facts have changed about special education. It is in the national interest to draw lessons for all schools in personalising learning, transforming approaches to learning through the arts and arts therapy, creating a place for the arts in the national curriculum, and drawing on the resources of the whole community.

Brian Caldwell is managing director of Educational Transformations and a former dean of education at Melbourne University. This article draws from his address to the "Re-imagining special education" symposium.

Advances by intellectually disabled man cost his life

Harriet Alexander August 13, 2008

GERARD FLEMING had met other men at gay beats on the northern beaches, but the intellectually disabled man's advances towards a teenage boy in the Narrabeen public toilets known as "the tram shed" cost him his life, a court has been told.

A teenager pleaded not guilty in the Supreme Court yesterday to murdering Mr Fleming.

The Crown prosecutor, Margaret Cunneen, SC, told the jury that the two had shared some beer while sheltering in the toilets on a rainy night in June last year. Mr Fleming, who suffered from a form of autism called Asperger's syndrome, had gone to the area, which was known by locals as a place frequented by homosexual men, after spending the night with friends, while the teenager had been to some parties.

But the teenager, who cannot be named, allegedly stabbed Mr Fleming with a folding knife after the 35-year-old emerged from one of the cubicles with his trousers down and joked that he wanted to give his new friend "a wedgie", Ms Cunneen told the jury.

The boy later told friends he had stabbed Mr Fleming in self-defence, after the older man had tried to "roll", or rape, him. Mr Fleming survived long enough to tell police the first name, school and age of the person who had harmed him and, as he lay dying in the ambulance, explained they had met that night at the nearby toilets, Ms Cunneen said.

The prosecution will screen a police video showing the boy walking police through the area and pointing out where he deposited the knife and clothing he was wearing on the night.

Ms Cunneen told the jury the issue would not be whether the boy's actions resulted in the man's death, but whether they could be justified. "I don't expect that the issue in this case will be whether or not the accused will be the person who killed Gerard Fleming," Ms Cunneen told the court. "The issue will be what level of culpability he had when that stabbing took place."

Mr Fleming's neighbour, Diana van Bell, told the jury he had confided in her he was gay and occasionally met men at gay beats in the northern beaches, including the "tram shed" where he had once laughed about meeting a transvestite.

She had lent him books to help him reconcile his religious views with his sexuality. Another friend, Diane Mantell, said it was obvious to anyone who met him that Mr Fleming had an intellectual disability. "Gerry was like a child in many ways," Ms Mantell told the court.

"He was very jovial and whatever he did, he enjoyed his adventures."

This story was found at:
http://www.smh.com.au/articles/2008/08/12/1218306901720.html

Editor's note: The DSM-IV diagnostic criteria for Asperger's disorder state …

> *E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behaviour …*

In other words, Asperger's syndrome is incompatible with intellectual disability. We cannot tell whether the court or the media, or some other agency, has got its facts wrong. If they cannot get basic aspects of the case right there is little prospect the public will get accurate information in matters.

The SMH responded "Since receiving you email we have contacted the family of the deceased man who inform us that in addition to being diagnosed with Asperger's disorder he also suffered from an intellectual disability. The family do not believe there to be any need for a correction or clarification."

Suffering loose words

Gerard Fleming's death was a tragedy but your report should not have exacerbated it by describing him as someone "who suffered from a form of autism" ("Advances by intellectually disabled man cost his life", August 13).

He did not suffer from an autism spectrum disorder, he simply had it.

Language can insidiously define how society views all disabilities. People with disabilities deserve respect, not pity.

Karen McEwen North Turramurra
SMH Letters August 15, 2008

A plan to live without fear from bullying

Herald Sun Meredith Ward, August 25, 2008 12:00am

WOULD you do more to stop a bully if you knew it was going to save a life?

Many government policies encourage us to include people with a disability. The language we use to describe them has changed over the decades to be kinder. But little else seems to have changed, especially for those whose disability is "hidden" — as with autism.

Children and teens still taunt and tease others who are different.

They always have.

It appears that bullying for "Tom" - a 15-year-old with Asperger syndrome who lived in the Geelong area - became such a burden that it was a factor in his suicide last weekend.

read more at *http://www.news.com.au/heraldsun/story/0,21985,24233498-5000117,00.html*

Letters

DAN Conference deal

Dear Community;

Mindd has arranged a 2 for 1 deal for any of the Mindd-Australasia community for all DAN! conferences. This applies to professional and parent streams. If you are interested in attending and/or finding a partner, please email info@mindd.org and title it DAN! San Diego.

Please note that Dr. Robyn Cosford will be presenting at the upcoming DAN conference.

Australia stands to gain a lot by developing international ties across parent and professional lines. So come along if you can. For more information, visit the DAN! conference site

Health & Happiness!

The Mindd Team

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Thank you for the newsletter ... two points I would like to make in response.

Government fails yet again to recognise those of us with children who are over 12 years of age who were late diagnosed and have received no family support, respite etc.

Education is a joke and leaves us in many cases nothing but home schooling as an option and if we are able to access services there is no financial support.

This is political spin at its best and sadly will not result in meaningful support for my child and many of my friends' children, and does not take into account our urgent need.

I also seriously question the number of children actually diagnosed under 6 years particularly the High functioning and Aspergers children.

I so do support those with new diagnosis under 6 years, but what about our vulnerable teens? Talk to our leading experts who will tell you about: the high suicide risk; the high risk of severe bullying by peers; the lack of resource for employment. The list is long and surely they are important as they have been long neglected. Surely we should be helping to fix those already damaged by lack of services or are they to be written off!!?

Secondly, I am totally sick to death of editorial that says Aspergers Syndrome is a mild form of autism. If anyone would like to take the time to talk to me about how it is for our family, my son and many for our friends I am sure you would not leave with the impression that this is a mild disability!!! This type of editorial is misleading and condescending. I hope I do not offend but my frustration is extreme.

Sandy Gray

26/7/2008

Dear Sir/Madam,

I found this edition of the A4 Newsletter very encouraging. Even though my autistic son is 18 in October it is gladdening to see some in the public service/government are finally taking some notice of those on the coalface with autism. I will be sure to pass this newsletter onto my local support group as I know some will find it very helpful indeed. Keep up the good work all of you at A4.

Yours Margaret.Bray. Maryborough, QLD

26/7/2008

Dear Bob, thanks for the latest newsletter, which focuses on the Govt $12k grants. Please find attached a copy of the e-mail I sent to Glen Dorahy and some MPs (Ministers Macklin, Roxon, and Joe Hockey) regarding to lack of any funding for the biomedical approach.

I also agree with your concerns about the capacity of the existing workforce in the allied health sector to meet demand, and whether they can organise themselves into consortia to meet the application requirements set out in the FaHCSIA website. I think the money should simply be reclaimable under a Medicare item number, or numbers, rather than having additional bureaucracy and all these small units being set up, inevitably incurring probably at least half the funding in admin fees. There has got to be a better way....Regards. Dennis.

> Helping Children with Autism Package
>
> Dear Glen Dorahy,
>
> With reference to the above I note that there is no opportunity for any biomedical approach to autism to be included. This appears to me (and numerous others) to be a most serious oversight as there are many doctors in Australia who provide outstanding treatment autism on a day to day basis, and get absolutely no recognition from any Government.
>
> Autism is a biomedical condition derived from either a genetic failure and/or an environmental insult. As such it requires early intervention, not only from the psychologists and other therapists, but more importantly, from the physicians/general practitioners.
>
> There is ample evidence produced by eminent doctors and researchers in the USA and Europe, as well as here in Australia, for the existence of major imbalances in amino acids, fatty acids, other organic acids, glutathione ratios, as well as the existence of heavy metals in many autistic children. These problems need to be addressed by the appropriate dietary and medical

> protocols in order to provide early relief of autistic symptoms. Psychological and other therapies will take so much longer to produce results (if at all) if the underlying biochemistry is not being sorted out at the same time.
>
> Please explain why this is apparently not being catered for in the allocation of funding.
>
> Yours sincerely
>
> Dennis Crowley
> D M Crowley and Associates
>
>> ----- Original Message -----
>>
>> **From:** Bob Buckley - A4 Convenor
>> **To:** Dennis Crowley
>>
>> Hi Dennis ... would you like me to publish your letter in the next A4 Update?
>>
>> regards
>> Bob Buckley

Hi Bob, Yes please. I have been thinking that talking about a biomedical approach to autism in Government and many well meaning health authorities circles, one gets the impression that it is some sort of underground movement trying to pervert the "only true path to a better life for autistic children" ie the psychological one. You could call it the Autistic Samizdat (AS), a network of concerned parents who believe there is another way to helping solve their children's problems by sharing dietary and other biomedical information which is not considered 100% proven, as in double blind crossover placebo (DBCP) tested.

As you are no doubt aware, Jan Brenton's Biomed, Leslie Embersits' MINDD, as well as Marion Redstone's Pfeiffer Walsh groups (and the doctors/health professionals they know), all help hundreds of parents on a daily basis. The Federal and State Governments completely ignore the good work they are doing and appear to be either unwilling, or unaware of, the benefits of integrative medicine in the treatment of autism. As a result hundreds more children and families are being left with little or no support, and having to make the best of their very difficult lives. What can we do to lift the bureaucratic blindfolds?

Your work at A4 has certainly brought about a change in Government attitudes towards autism, and we are all very grateful to you for it. However, as you say in your newsletter it is but a first step. Let's keep it moving. Kind regards. Dennis.

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

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