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A4 website renewal

Recently, we gave the A4 website a major facelift. It is still at the same old address: a4.org.au. The old website is still available but it will eventually disappear.

The renewed website is meant to help A4 members participate more in what A4 does on behalf of our community. You can comment on articles on the website. You can raise topics in the online forums and have your say on issues you care about. Please take a look at A4's new website. Even better, contribute to it. Go for it!

We will continue to deliver A4 Updates to people who join/register with the website. People can maintain their membership information on the new website, so we encourage people to register.

Just remember that A4 is about a variety of views on ASD-related issues. Please accept that some people have views that are not the same as yours. A4's strength is how it represents the range of views of its members.

So please use the website or email to tell us your views on ASD-related issues. If you see someone expressing a similar view to your own, then say so ... we need good support for shared views. A4 depends on its members and its success depends on how it represents its members' views to the federal (and sometimes state) government, and to the community.

We know people have different views. We do not need the differences explained. Different views arise from different experiences. A4 does not need criticism of views that are the result of close personal experience of ASD.

We should focus on ways to improve the lives of people who live close to ASD. It is clear that there is a variety of experience and we need varied approaches to the range of challenges and experiences.

Please let the website reflect positively the diversity of our community.

A4 still needs volunteers to achieve its ends. If you can help, either with getting relevant material onto the website ... or with the very technical aspects of a website like this, please let us know (email to cnvnr@a4.org.au). If you have ideas about how to improve our website, then tell us.

We do not pay for media monitoring. If you see something anywhere in the media that is autism/ASD related, please let us know.

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Your say about the National Disability Strategy

The Australian Government is developing a National Disability Strategy ... in close consultation with the Australian community, disability and carer peak bodies, employers, industry experts and state and territory governments.

As well as last month’s consultation, you have another chance this month to help the government understand what people with ASD need. For more information visit the FaHCSIA website ...

<http://www.fahcsia.gov.au/internet/facsinternet.nsf/disabilities/nds.htm>

Convenor’s message

Dear A4 member,

A few people have commented to me that A4 Updates needed to be a bit more colourful so I have given the publication a bit of a facelift. I hope you like it.

Others have commented that A4 Updates are too hard to read: that that the writing is at times too technical in style ... that it can be challenging for people who are not familiar with more formal or scientific writing. Similarly, some people comment that the Updates are very important to them. Hopefully the balance is about right, so unless I get a strong reader reaction to these few words, I will leave it as is for now.

The whole of the federal Government's Helping Children with Autism (HCWA) package is now underway. The contracts for Autism Advisors around the country are now operational. The advisors in each area know who the Early Intervention providers on the Panel are.

Families whose child is eligible for HCWA-funded Early Intervention should contact an Autism Advisor in your area. Children who will become ineligible soonest will get priority to see an Advisor. The Advisor is needed to register with FaHCSIA to pay for the recognised service providers.

While this "initiative" is in my view a less-than-ideal response to the challenges due to autism and ASD more generally, it is a significant start. HCWA recognises a need to do something. It will be a significant learning experience for governments at both the federal and state levels.

There are other services to access. If you need allied health services (behavioural intervention, speech therapy, OT, etc.) you may be able to access them via a paediatrician (you may need to get a referral from a GP). There are play groups, and various parent workshops being funded as part of the HCWA package. Make sure you access these if they could help.

In Australia, autism does not yet have the sort of prominence that the US Presidential campaign gave it.

If you do access these services, please provide feedback to your politicians; especially your federal politicians. Tell them both what you thought was good about the services and what did not work for you. And remember to tell them if there are crucial services that you cannot access. Please take the time to let your representatives know. Your efforts are needed to make them aware of the issues. And please let us know as well.

Congratulations to Peter Hill for his efforts to fund autism research (see *There's more to Dapto than the dogs* below). Peter managed to raise these funds as well as help with the Parliamentary Breakfast, contribute to the A4 Steering Committee and supporting ASD-related activities in general.

In recent times, activities in my region, the Australian Capital Territory, have drawn me away from A4. The recent election is creating a new local government. There were different responses from the three main parties who will be represented in the ACT Legislative Assembly.

ACT Labor made a number of election announcements that in my opinion reflect a particularly poor understanding (and absence of consultation) of ASD-related matters. We can but hope the election result will help them realise that they need to take a different approach over issues like autism/ASD.

The ACT Liberals were more receptive. They did discuss the needs of people with ASD and their policy was more sympathetic. It seems likely, if political commentary is accepted, that their electoral result was due to issues other than ASD.

The ACT Greens chatted with us but decided they did not have the capacity to develop ASD-related policy prior to the election. One of their candidates (who did get elected) committed to discussions with us in the event that they won a place in the Assembly. Given their success in the election, we hope those discussions will start soon.

A report of one study I noticed this month said *People With Autism Make More Rational Decisions* (see <http://www.medicalnewstoday.com/articles/125627.php>). Maybe you can use this in arguments with people whose decisions just do not make sense. You can try arguing that even for those of us who do not have a diagnosis, having a child with a diagnosis shows we are likely to be partly autistic ... so on the basis of evidence our decisions are likely to be more rational ☺

Regards
Bob Buckley
31/10/2008

Concern arises from Inquiry into Disability Trusts

Recently, the Senate issued its report from its Inquiry into Special Disability Trusts. While Special Disability Trusts seem to have little relevance for people with ASD, their families and friends the Inquiry has revealed an issue of considerable concern.

The Report quotes from FaHCSIA's Submission No. 13 (see http://www.aph.gov.au/senate/committee/clac_ctte/disability_trusts/submi...) that says

Many people with disability, such as those with mental illness or impairment (for example autism, schizophrenia, bipolar or obsessive compulsive disorders) may not require care on a daily basis yet they may require ongoing care and supervision in relation to their financial and administrative affairs. At present, people in these categories may not pass the level of care criterion and therefore may not be eligible to be a beneficiary of a Special Disability Trust. (page 7)

While it may be correct technically to say **many** people with autism may not require care on a daily basis, such a statement could also be quite misleading. The article *AIHW reporting on autism* below shows that 50% of people who report on their autism say they need help with Activities of Daily Living on a daily basis. These data show that fewer than 10% of people with “autism” are relatively independent.

A4 members are invited to comment (go to <http://a4.org.au/a4/node/53>) on whether A4 should write as an organisation to FaHCSIA, the Minister and to the Senate Committee to ensure that they are aware that around 50% of people with “autism” need assistance with their “activities of daily living”. Should A4 use this opportunity to increase awareness in the Government of the autism spectrum and the needs of the people it affects?

AIHW reporting on autism

A number of recent reports released by various federal government agencies make mention of autism in various ways.

In October 2007 (around election time), the Australian Institute of Health and Welfare released its report *Disability support services 2005-06: National data on*

services provided under the Commonwealth State/Territory Disability Agreement¹. Chapter 4 of the report is headed *Service users with autism spectrum disorders*. It says ...

According to the 2003 ABS Survey of Disability, Ageing and Carers, an estimated 30,000 people had autism as a health condition (AIHW 2007 forthcoming). Of these, 24,100 (80%) also reported a severe or profound core activity limitation¹⁰. This equates to a prevalence rate of 0.1% of the Australian population (AIHW 2005c). There is an increasing trend in the estimated number of people with autism – since 1998 the number of people with autism has doubled from 13,000 people (including 12,400 as a severe or profound core activity limitation) (AIHW 2007). This trend is at least partly due to increased public awareness about autism spectrum disorders and a greater understanding by the community and medical practitioners in the diagnosis and/or reporting of autism.

While the report is very dry in its presentation, it gives us some cause for concern. For example, the following table is extracted from Table 4.3. I added an extra row to the table to show the difference between people with ASD and the average for people with a disability.

	Accommodation support (%)	Community support (%)	Community access (%)	Respite (%)	Employment (%)
autism total	16.9	65.6	23	29.2	15.2
all CSTDA service users	16.4	44.5	22	12.6	33.7
<i>difference</i>	<i>3.0%</i>	<i>47.4%</i>	<i>4.5%</i>	<i>131.7%</i>	<i>-54.9%</i>

People with autism, back then in 2003, used proportionally more disability services in most categories than people with other disabilities, except for employment services. It is not clear whether the low use of employment services was because most people with “autism” are not old enough to be employed, or if these data are only reported for people of a relevant age then the high use of respite and low use of employment services may reflect a particularly poor outcome for people with autism.

There are several ways the boffins compare the degree of disability. One method is to ask people to say what their degree of disability is. Another method asks how often a person with a disability needs help with “activities of daily living”. The report shows the result. Following is another comparison from two tables, Tables 4.4 and 3.7, in the report.

	Always unable to do	Sometimes	None, but uses aids	None
autism				
Any ADL reported	47.7%	38.5%	0.9%	6.7%
	50.9%	41.0%	1.0%	7.1%
All disability types				
Any ADL reported	23.2%	35.9%	3.4%	15.1%
	29.9%	46.3%	4.4%	19.5%

¹ See <http://www.aihw.gov.au/publications/index.cfm/title/10488> or download the report at <http://www.aihw.gov.au/publications/dis/dss05-06/dss05-06.pdf>

It shows that just over half the people with autism (who responded to the question) always need help with some activities of daily living. This is much higher than the people with a disability generally.

Fewer than 10% of people with autism who receive any kind of service are independent in their daily living: they do not need help with ADLs.

Another recent AIHW report, *Disability in Australia: trends in prevalence, education, employment and community living*², also includes some comments about autism. It says ...

- A rise in the reported prevalence rates of disabling conditions associated with childhood such as attention deficit hyperactivity disorder and autism-related disorders resulted in a substantial increase in the reported number of children with a disability in the past decade. (page 2)
- For children aged under 15 years, the age-standardised rates of severe or profound limitations increased over the two decades. This was partially attributable to an increase in reporting long-term health conditions associated with childhood, especially attention deficit hyperactivity disorder (ADHD) and autism-related disorders. (page 8)
- Substantial increases in the number of children aged under 15 years with severe or profound limitations in the 1998 and 2003 surveys (Figure 3) were largely due to a rise in the reported prevalence rates of some disabling conditions associated with childhood, especially ADHD and autism-related disorders. Both higher levels of diagnosis and heightened awareness among parents, educators and health professionals may have contributed to the increase in reporting these conditions. (page 10)

Table 4: Changes in the prevalence of selected long-term health conditions, by disability status, 1998–2003

	1998		2003		1998-2003	
	Number ('000)		Number ('000)		Change (per cent)	
	With disability	Severe or profound	With disability	Severe or profound	With disability	Severe or profound
Migraine	55	13.8	257	69.4	367.2	404.8
Osteoporosis	72.5	37.5	242.5	109.7	234.6	192.6
Autism	12.4	12.4	29.9	24.8	141.4	100.2
Depression	177.3	75	333.1	142.1	87.8	89.4
...

This shows the number of people with severe or profound autism doubled between 1998 and 2003. The rising diagnosis rate was 3rd highest for “autism”, higher than the change in reporting of depression.

These reports present the same old data³ from 1998 and 2003 from the *ABS Survey of Disability, Ageing and Carers*. A4 reported previously that these data are

² See <http://www.aihw.gov.au/publications/index.cfm/title/10495> and <http://www.aihw.gov.au/publications/aus/bulletin61/bulletin61.pdf>

³ These data were first published in the only peer reviewed paper on ASD prevalence in Australia so far ... Bob Buckley, (2004) *Autism/ASD diagnosis rates in Australia* in Proceedings of the Australian National Autism Conference 2004 (see http://autism.anu.edu.au/pdf_files/buckley_submit2.pdf).

consistent with the Centrelink data that underpin the oft-cited Australian report on prevalence⁴.

Reports like these will be much more useful when they include another dataset. The *ABS Survey of Disability, Ageing and Carers* was due to be repeated this year (2008) but we have now to wait until next year. (ABS staff keep saying they will consult the ASD community about this survey ... but they never get around to it ... so it goes).

Autism in the US presidential debate

The subject of autism was surprisingly prominent in a recent US Presidential debate⁵. Describing Ms Palin, McCain said ...

She'll be my partner. She understands reform. And, by the way, she also understands special-needs families. She understands that autism is on the rise, that we've got to find out what's causing it, and we've got to reach out to these families, and help them, and give them the help they need as they raise these very special needs children.

Then Obama said ...

I do want to just point out that autism, for example, or other special needs will require some additional funding, if we're going to get serious in terms of research. That is something that every family that advocates on behalf of disabled children talk about.

McCain again ...

And I just said to you earlier, town hall meeting after town hall meeting, parents come with kids, children -- precious children who have autism. **Sarah Palin** knows about that better than most. And we'll find and we'll spend the money, research, to find the cause of autism. And we'll care for these young children. And all Americans will open their wallets and their hearts to do so.

Commentary for the ASD community questions whether having a child with Down's syndrome is a sufficient basis for understanding about autism.

There is no doubt that the ASD community in Australia would like this level of awareness in Australian political discussion.

⁴ See *Data from Centrelink on Autism Spectrum Disorders*, the lead article in A4 Update (Dec 2006) Volume 4, Number 7.

⁵ transcript and commentary from the community available at <http://latimesblogs.latimes.com/washington/2008/10/debate-transcri.html>

Government ignores autistic kids

Sue Napier MP

Shadow Minister for Education

Tuesday October 28, 2008

The State Opposition has today expressed alarm about the number of autistic children who the Department of Education are trying to manage through Distance Education, and the number of children who are supposedly enrolled in school but not receiving assistance.

Shadow Minister for Education, Sue Napier, today raised the matter in Parliament as a Matter of Public Importance.

“We are advised there may be some 33 new enrolments into Distance Education of children with autism in this State this year alone and possibly 50 or 60 children with autism inappropriately being educated by a Distance Education system that cannot assist them with their education,” Mrs Napier said.

“We are being told by families of these children that they are left with no other option for education in this State because their children cannot cope in the mainstream schools system.”

Mrs Napier said that the Premier’s suggestion that children with autism can receive funding of \$16,000 was misleading, because it only applied to children suffering from very high levels of the condition and only a small percentage of children with autism would therefore be eligible for assistance.

“Even then, children with autism are not provided with adequate teaching aide hours and teachers and teacher aides are not provided with appropriate training and resources to support their learning, let alone develop a targeted Individual Education Program,” Mrs Napier said.

“The Premier also fails to acknowledge that people who suffer from Asperger Syndrome are not eligible for special support. The irony is that these kids could particularly benefit with accessing the Talented and Gifted programs.”

Mrs Napier said the Education Department’s recently released Disability Action Plan 2008-2010 failed to pick up many of the key recommendations in the submission from the Tasmanian Childrens Commissioner, Paul Mason, including for example, the suggestion that a program for autistic children needs to be at least 20 hours per week over an extended period of at least two years with continuing support thereafter.

“As Professor Brian Caldwell has said, successful education systems in the world have broadened their definitions of special needs and provide one-to-one and small group special assistance for all children who are falling behind,” Mrs Napier said.

“The Tasmanian Liberals believe that we need to seriously consider this new approach and children with autism would certainly fall into that category.

“We have even heard of one instance where the Department was going to co-enrol a 9 year old at Hobart College and Distance Education, which sounds more like a

statistical exercise than using an evidenced based approach for the education of children with autism.

“The seriousness with which the Premier considers this issue is evidenced by the fact that he wasn’t even in the House during the debate. Instead, we got a Departmental-like response from his Parliamentary Secretary, Lisa Singh.

“The reality is that the current attempts to respond to the needs of children with autism are not working. Indeed, through ignorance, State Government programs for children do nothing more than babysit them.

“The Premier would have had enough complaints coming through his door to guarantee that he is well aware of the issue.”

For further information or comment please call Kristy Mays – 0407 503 910

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Convenor’s note: The practice of “including” students with ASD in distance education is questionable at best. It seems the goal is for the Tasmanian Education Department to avoid responsibility for actually teaching children with ASD.

Australia leads support for people with disabilities

Media release: <http://www.bobmcmullan.com/?q=node/405>

Parliamentary Secretary for International Development Assistance, Bob McMullan, today committed Australia to a leadership role in supporting people with disability in the Asia Pacific.

An estimated 650 million people across the world have a disability and about 80 per cent of the population with a disability live in developing countries. The Asia Pacific region is home to two-thirds of this population.

“The Australian Government recognises that poverty is both a cause and consequence of disability and is committed to ensuring that the benefits of development reach those who are most excluded,” Mr McMullan said.

Convenor’s note: First. poverty is not a cause of autism.

Second, Australia needs to do a lot more to earn credibility on this subject. So far Australian Governments have refused to enact the legislation required under these international treaties, so the treaties have no effect in Australia. It is not credible to comment on other countries in the Asia Pacific region when Australia has not done what it is required to do.

Autism Speaks pushing US States to make Insurers cover Behavioural Therapy

The advocacy group [Autism Speaks](#) in 2009 will target at least 10 states -- including New York, California and Ohio -- to push for legislation that would require health insurers to cover autistic behavioral therapy, the [AP/Contra Costa Times](#) reports. The group already has endorsed bills in New Jersey, Virginia and Michigan. Indiana, Texas, Pennsylvania, Arizona, Florida, South Carolina and Louisiana already have approved such coverage mandates. Other states also have approved coverage mandates but are not working with Autism Speaks. Supporters of behavior therapy for autism say that it is supported by decades of research and that it will promote long-term savings by keeping afflicted children out of institutions. The therapy can cost up to \$50,000 annually.

See more at <http://www.medicalnewstoday.com/articles/126128.php>

United Nations World Focus on Autism

Forum Held in New York

From http://www.autismspeaks.org/inthenews/united_nations_world_focus_on_a_utism_gaph.php

[Click here for a photo gallery from the event](#)

On September 26, 2008, more than 150 First Ladies and dignitaries, including Mrs. Ban Soon-taek, wife to UN Secretary General Ban Ki-moon and Mrs. Sarah Brown, wife of the British Prime Minister met in New York to discuss the global epidemic of autism.

Organized and hosted by Mrs. Suzanne Wright, co-founder of Autism Speaks, the largest non-profit autism research organization in the world, the international coalition representing 55 countries was a striking endorsement of the UN efforts to raise autism awareness. Those attending included first ladies from Albania, Bahamas, Cameroon, Cape Verde, Cyprus, Mali, Panama, and Poland as well as spouses of ambassadors. This distinguished group heard from a world-class panel of experts and discussed an international pathway to raising global awareness and promoting research into this non-discriminative disorder.

In her opening remarks, event chair Mrs. Ban Soon-taek welcomed the international group on behalf of her husband UN Secretary General Ban Ki-moon and stated that, "it is still sadly a reality that in some parts of the world, those affected by autism-related disorders are set aside, placed in institutions or dismissed as untreatable lost causes." Mrs. Ban continued to say that "it is crucial that professionals and society at large become more involved, compassionate and accepting of this complex condition." Co-chair Mrs. Dorrit Moussaieff, First Lady of Iceland shared her personal reflections on Autism Speaks Co-Founders Bob and Suzanne Wright. "The energy and commitment of Bob and Suzanne to raising awareness of and funding research into autism has been an inspiration to me as to all who come in to contact with them."

Calling for action, event host Suzanne Wright asked the international delegation convened, "not just as the co-founder of Autism Speaks, but as a grandmother of

a little boy who has slipped into the silent world of autism to please lend your voices and stand united with us in our worldwide campaign. By recognizing World Autism Awareness Day every April 2nd until a cure is found, you will help to shine a global spotlight on autism.” Bob Wright, shared some of the staggering statistics with the room, “it is estimated that approximately 1% of the global population has autism – 67 million worldwide” Wright said in his remarks.

Global Autism Public Health Initiative (GAPH)

During the event, Autism Speaks unveiled its Global Autism Public Health Initiative (GAPH), designed in response to the call to action put forth by the speakers at the event and presented in a panel discussion moderated by CNN Chief International Correspondent Christiane Amanpour. Participating in the panel were: Autism Speaks' Dr. Geraldine Dawson, Chief Science Officer; Dr. Andy Shih, Vice President of Scientific Affairs; and Ms. Alison Tepper Singer, Executive Vice President; as well as Mr. Hassan Ali Bin Ali, Chairman of the Shafallah Center for Children with Special Needs and Dr. Hatem El Shanti, Director of the Shafallah Genetics Medical Center.

GAPH is an ambitious international advocacy effort aimed at increasing public and professional awareness of autism spectrum disorders (ASD) worldwide. This Initiative also strives to enhance research expertise and international collaboration through training of autism researchers – with a focus on epidemiology, screening and early diagnosis, and treatment – and to improve service delivery in all nations by providing training to providers in early diagnosis and intervention.

As part of the awareness component of GAPH, Autism Speaks will help others emulate its highly successful U.S. awareness campaign, which has dramatically increased public and professional recognition and understanding of ASD and supported the passing of significant federal and state legislation aimed at enhancing research and services.

In the area of training and scientific collaboration, GAPH is focused on building research capacity worldwide by encouraging the adaptation of standardized screening and diagnostic instruments for cultural relevance and sensitivity with the goal of ensuring accurate diagnosis and early detection of ASD. Additionally, Autism Speaks' International Autism Epidemiology Network (IAEN) provides a platform for collaborative research through the exchange of epidemiologic ideas and practices between investigators and across countries.

The services training and delivery component of GAPH is based on the understanding that effective treatments involve close collaboration between professionals and families, and require sensitivity to cultural perspectives and values. GAPH will offer information and training regarding empirically supported “best practices” that can be tailored to the specific needs, cultural preferences, and values of a given territory.

“GAPH is an effort to form global partnerships that will improve our scientific understanding of autism and help the world better understand the scope of this unique health crisis,” said Dr. Dawson. “Perhaps most importantly, it will help build the infrastructures needed to provide individuals who have autism with the services and support they need and deserve. We will find the answers we seek about autism only through international cooperation and collaboration,

partnerships forged in laboratories, governmental chambers and homes across the world.”

Autism Speaks is seeking partners worldwide who will work with the organization to foster collaborations among governments, communities, and scientists, as well as help to support self-sustaining public health infrastructures to enhance awareness and capacity for autism services and research in their respective countries. Differences in resources, infrastructure, culture, and priorities will require a customized plan of action for each territory.

Read coverage of the *United Nations World Focus on Autism Forum* from the [Associated Press](#) and [CNN](#) and see [video from CNN](#).



VOLUNTEERS NEEDED

FOR A RESEARCH PROJECT ON ATTACHMENT RELATIONSHIPS, SOCIAL UNDERSTANDING AND RESPONSIVENESS IN CHILDREN WITH AUTISM

A new study is underway at the Olga Tennison Autism Research Centre at La Trobe University examining the way children with autism think about their relationships with caregivers, their ability to think from another person's point of view, and their social and emotional responses to others in social situations. Children who have been diagnosed with Autistic Disorder or Autism Spectrum Disorder aged between 8 to 12 years and who are high functioning with good verbal ability, along with one parent or caregiver, are invited to participate.

The testing will take place over two sessions at the Olga Tennison Autism Research Centre at La Trobe University. The results of the developmental assessment undertaken as part of the study will be available to parents free of charge. If you and your child would like to participate or if you wish to obtain further information about this research, please contact Dr Cheryl Dissanayake at the School of Psychological Science, La Trobe University, Bundoora, 3083 (Tel: 03 9479 1162; email: c.dissanayake@latrobe.edu.au), Ms Felicity Chandler (Tel: 03 9479 2151; email: f.chandler@latrobe.edu.au) or Ms Amanda Newbigin (Tel: 03 9479 2151; email: a.newbigin@latrobe.edu.au).

Transporters DVD Pack

— helping children with autism learn about emotions

"After only watching three or so episodes my son knew the names of every character... he then said to me, "Look, Daddy's happy." This was the first time he'd said this. Ever."

This is an actual quote from the parent of a child with autism after his son had watched The Transporters, a series designed to help children with autism understand and recognise emotions. It was developed by The Autism Research Centre at Cambridge University in conjunction with the UK government. You may have heard about it on ABC and in the press recently.

Now available in Australia

Parents, carers and teachers in the UK have been using The Transporters for 18 months. I'm delighted to say it's now available to buy in Australia too.

The DVD Pack is available for purchase by credit or debit card at www.thetransporters.com.

At least 25% of profits from the sale of the DVD go to autism charities.

The DVD has been specially designed to work perfectly in Australia and New Zealand. Delivery time is currently about 5 days.

"It's a bit like someone flicked a switch on in his head"

This is another of the wonderful things parents have said about the DVD Pack. You can read other testimonials from parents, carers and professionals at <http://www.thetransporters.com/say.html>

Based on careful scientific research

Research conducted by the Autism Research Centre shows that after using the DVD Pack for four weeks most children with autism caught up with other children in their ability to recognise emotions. You can find out more and watch a short movie about the research at <http://www.thetransporters.com/research.html>.

A fun cartoon world with real human faces

The team behind The Transporters wanted to create a series children with autism would love that would teach them about emotions at the same time. They set about inventing eight lovable vehicles, specifically designed to appeal to children with autism. These trains, trams and cable cars have adventures based around 15 key emotions. Cleverly, the vehicles have real human faces so the children learn to recognise emotions on real faces rather than cartoon ones. This helps them to generalise.

What's in the DVD Pack

- 15 fun five minute episodes, showing key emotions in context;
- 30 entertaining interactive quizzes to reinforce and test understanding;
- 36-page booklet explaining how to get the most out of the DVD at home and at school.

Letting people know

I notice that you run a support group for parents and carers of children with autism and I wonder whether you would be kind enough to bring the DVD Pack and its benefits to the attention of your members.

If any of your members use the DVD Pack, we'd love their feedback to make future series even better. It's important to us that The Transporters works for parents and children alike.

Also, if you know someone who could benefit from The Transporters, please feel free to pass this email on. We have a flyer which you might like to use if your members prefer printed materials. I didn't attach it to this mail in case your spam filters stopped it but I hope you don't mind if I send it in a separate mail in a few days time.

With very best wishes

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In the news

New World Disorder

Alexander Gambotto-Burke has a major article about autism and Asperger's published in the bi-monthly Australian magazine, Men's Style. Previously, articles have appeared in the predominantly women's magazines. Now there is a feature article in a men's magazine. It all helps to increase awareness of autism spectrum disorders.

There's more to Dapto than the dogs

See <http://www.wollongong.youronlinecommunity.com.au/article.cfm?article=F9A65F6D-1143-CE49-CB284FEB76913ACB>

Dapto is famous for its greyhound meetings but the local Rotary Club has moved into the limelight with its strong support for the battle against autism.

The driving force behind the club's support – they recently handed over a cheque for \$20 000 to The Australian Rotary Health Research Fund – has been member Peter Hill, himself a parent of a 17 year old son Matthew who suffers from the dreaded complaint.

Peter says that the club's \$20 000 donation when combined with The Australian Rotary Health Research Fund's Funding Partners scheme meant that in all \$36 000 became available to help the fight against autism.



Rotarian Peter Hill, with cheque



Joy Gillette, CEO of ARHRF being presented with the \$20,000 cheque by President Barry Brown

He also suggests that any clubs or organisations wanting to make a positive difference for children with autism can either establish their own funding project in co – operation with The Australian Rotary Health Research Fund or they can make a tax deductible donation directly to the Olga Tennison Autism Research Centre at Melbourne's La Trobe University.

A Rotarian of some seven years standing Peter held the position as director for youth and young adults and as a director for The Partners in Autism Project.

Born at Bowral and educated at the local high school he then trained as a technician with Telecom. He is currently Communications Project Manager at the University of Wollongong.

Peter says his son Matthew has considerable difficulty in communicating his needs to the family and at times he can become very anxious.

He also says Matthew has difficulty at times in understanding what the family is trying to get across to him.

The severity of Matthew's autism means he needs help with all areas of his life from dressing, bathing, preparation of food and while he can walk and run he has no concept of the danger from traffic.

"It means Matthew needs supervision at all times during his waking hours," Peter says.

One single phrase says it all

Peter says to be told in one single phrase "your child has autism" extorts enormous emotional, social and economic costs to your family.

In a report by the Synergies Economic Consulting in 2007 titled The Economic Costs of Autism Spectrum Disorder it was estimated the disease cost the Australian economy between \$4.5 to \$7.2 billion.

With this information in hand the Dapto Rotary Club, he says, decided to take some positive action.

"The members understood the impact on a family of having a child with autism and made an early commitment to link up with The Partners in Autism Research Project", Peter says.

Autism Spectrum Disorder (ASD) is a neurological condition that affects a person's ability to speak, communicate, socialise, learn, play and behave in an appropriate manner. Its cause is not known, but it is diagnosed in approximately one in every 160 children under the age of six years with boys four times more likely to have the disorder than girls.

Peter says that socially ASD can be particularly hard for parents as the triggers for many of these anxiety related behaviours do not appear obvious to other people, who simply see "a naughty child".

If you are interested in raising funds for the work of The Olga Tennison Autism Research Centre it can be contacted c/o School of Psychological Science, La Trobe University, Bundoora, Victoria 3086 or by telephoning 03 9479 3086.

The Centre's web site is www.latrobe.edu.au/otarc/centre

A clue to learning deficit in children with autism

High-tech eye-tracking equipment reveals autistic children look at a teacher's face less than normal children

A study by researchers at the UC Davis M.I.N.D. Institute has discovered an important clue to why children with autism spectrum disorders have trouble

imitating others: They spend less time looking at the faces of people who are modelling new skills.

The study was conducted using high-technology eye-tracking headgear and software that measures with precision the point at which a child is looking when learning a task. Researchers used an actor to demonstrate a task on a computer screen.

"We found that the children with autism focused on the demonstrator's action and looked at the demonstrator's face much less often than did typically developing children," said Giacomo Vivanti, a postdoctoral researcher at the M.I.N.D. Institute and the study's lead author. "The typically developing children may be looking at the demonstrator's face to check for information on what to do or how to respond appropriately, information that the children with autism are less inclined to seek. This is an important finding, because children with autism have difficulty learning from others. This might be one key to why that is so," Vivanti said.

Imitation plays an important role in how children learn, as well as in how people interact socially, said M.I.N.D. Institute researcher and senior study author Sally J. Rogers, who has been studying imitation impairment and autism for more than 20 years. "This is a trait we see as early as we can diagnose autism, and it's one of the traits that is present even in mildly impaired adults," Rogers said.

Impaired imitation leads to additional impairments in sharing emotions, pretend play, pragmatic communication and understanding the emotional states of others. For years, scientists thought that children with autism and related disorders had trouble with learning through imitation because they had poor motor skills or because they did not pay attention to the action being performed. The current study rules out these hypotheses.

"We now understand more about how this imitation deficit might be working and, after more study, we may actually be able to address it in a way that helps children with autism develop a more natural set of behaviours," said Rogers, a UC Davis professor of psychiatry and behavioural sciences.

For more, see http://www.eurekalert.org/pub_releases/2008-10/uoc--mir100908.php

Reaching an Autistic Teenager

On a typical Monday morning at an atypical high school, teenage boys yanked open the glass doors to the First Baptist Church of Decatur, Ga. Half-awake, iPod wires curling from their ears, their backpacks unbuckled and their jeans baggy, the guys headed for the elevator. Arriving at Morning Meeting in the third-floor conference room, Stephen, his face hidden under long black bangs, dropped into a chair, sprawled across the table and went back to sleep. The Community School, or T.C.S., is a small private school for teenage boys with [autism](#) or related disorders. Sleep disturbances are common in this student body of 10, so a boy's staggering need for sleep is respected. Nick Boswell, a tall fellow with thick sideburns, arrived and began his usual pacing along the windows that overlook the church parking lot and baseball diamond. Edwick, with spiky brown hair and

a few black whiskers, tumbled backward with a splat into a beanbag chair on the floor. ...

For more, see http://www.nytimes.com/2008/10/19/magazine/19Autism-t.html?_r=1&em&oref=slogin

Autism genes can add up to genius

Intellectual gifts and certain brain disorders are closely related

Some people with autism have amazed experts with their outstanding memories, mathematical skills or musical talent. Now scientists have found that the genes thought to cause autism may also confer mathematical, musical and other skills on people without the condition.

The finding has emerged from a study of autism among 378 Cambridge University students, which found the condition was up to seven times more common among mathematicians than students in other disciplines. It was also five times more common in the siblings of mathematicians.

If confirmed, it could explain why autism - a disability that makes it hard to communicate with, and relate to, others - continues to exist in all types of society. It suggests the genes responsible are usually beneficial, causing the disease only if present in the wrong combinations. "Our understanding of autism is undergoing a transformation," said Professor Simon Baron-Cohen, director of the autism research centre at Cambridge, who led the study.

"It seems clear that genes play a significant role in the causes of autism and that those genes are also linked to certain intellectual skills." ...

For more, see <http://www.timesonline.co.uk/tol/news/uk/article4882699.ece>

Autism speaks. It's time for the world to listen

This bewildering disorder is on the increase in Britain. A three-pronged approach can help both sufferers and carers

How does a child vanish in plain sight? Our grandson, Christian, used to watch trucks drive by and name them all - "fire truck", "mail truck" - until, suddenly, he had no more words. We used to go for walks on the beach until he could no longer tolerate the feeling of sand on his feet. Warm smiles were gone, too, replaced by eyes that would not connect with mine.

The boy who had brought so much joy and had been hitting all his developmental milestones was slipping away. At first, doctors told us it was because he had a new baby brother, or because boys are slower to develop. Our concern turned into panic as Christian became increasingly sick and disconnected.

Eventually, we learnt the real answer when Christian had autism diagnosed. We were stunned. Despite having spent decades in the media business, we knew little about the disorder, and although we had access to the best medical care, we were at a loss about what to do next. Christian's doctors told us "goodbye and good luck". As we struggled to understand autism and help our grandson, our personal quest became a public crusade.

This crusade is very necessary: 1 per cent of the population in Britain - more than 500,000 people - suffer from autism spectrum disorder, yet it is still met with a mixture of ignorance, prejudice or indifference. ...

For more, see

http://www.timesonline.co.uk/tol/comment/columnists/guest_contributors/article4995146.ece

Letters

employment in the IT industry

To the editor,

Here is a very interesting article on employment in the IT industry and asperger syndrome ... useful background for the government review of disability employment.

<http://www.computerworld.com.au/index.php/id:875771420;pp:1>

education will not solve all our kids' problems

The Editor

When I read the article on Disability and employment in the latest A4 issue I knew I had to respond as this is something which has been close to my heart for many years, and which is at present causing us a great deal of angst. I don't think it's as easy as it may sound.

My son is a high functioning Asperger and, like others, I thought that if he got an education he would be employable. He went to a private school, never had a day of exclusion, and never had any special assistance (although we helped him a lot at home). He graduated from year 12 in the Qld system with an OP10- no genius, but no slouch either. He went on to do a Bachelor of Multimedia, which he completed in the same time as his peers (although working twice as hard and not able to do a part-time job as well), and with the same smattering of Distinctions, Credits, and Passes. So, he achieved the educational outcomes, but was completely unable to get a job of any kind and went on the disability support pension. After 3 or more years a friend at the head of a medium sized company offered him a "grace" job- 3 days a week, 40 weeks a year, which he supplemented with his pension. It wasn't using his skills or interests, although he should have been able to do the work. He became more and more stressed, so that at the end of last year he ended up in hospital with psychotic depression, and was off work for more than 4 months.

This year his job was changed, and things seemed to be going well, until recently. We knew his medication made him very tired, and that he slept a drugged sleep for hours most afternoons he was at home, but we didn't realise that at work he was often disoriented in the afternoons as he became more tired. We also found out that while he can function normally most of the time, sometimes he inexplicably gets muddled and confused, and somebody will have to fix things up

for him or tell him to fix it. This is unacceptable to an employer. His hours have now been cut to 4 mornings a week so he can have the best chance to function well. He is being given every chance to succeed, and yet we have a young man with a degree, functioning at a level very much below that, working 16 hours a week, and still not always able to get it right. It is depressing, upsetting, and baffling and the future looks bleak.

So I don't think improving the educational outcomes will solve all our kids' problems. I wish I knew what would.

Anonymous

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.

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Anti-spam: change -at- to @ in email addresses.

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