



UPDATE

Autism Aspergers Advocacy Australia

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Issue 7

Social Skills Training Helps Adolescents With Autism

November 02, 2007

The challenges that autistic patients face become more pronounced during adolescence, a crucial period when many kinds of social behaviours are developed and when these individuals can become more keenly aware of their relationship difficulties. A paper by Dr. Eric Fombonne, Head of the Division of Child Psychiatry at the McGill University Health Centre (MUHC), published in the November 2007 issue of the Journal of Autism and Developmental Disorders describes the effectiveness of social skills training groups for autistic adolescents.

“This study shows that the social and interpersonal skills of autistic adolescents can be improved, and we established that our method is efficient and does not require significant resources,” said Dr. Fombonne.

Dr. Fombonne organized the first training group in 2002, with his colleagues Jack Strulovitch, social worker at the MUHC, and Vicki Tagalakis, therapist in psychiatry paediatrics at the MUHC. They wanted to address the needs of autistic adolescents who had no major delay in their language development or who were not cognitively challenged (high-functioning autism and Asperger syndrome). Since then the training groups have been running twice a year for 14 sessions, each group involving seven to eight adolescents aged an average of 14.6 years.

The major component of the sessions is role play, which allows the patients to simulate different social situations and create new friendships with other members of the group. Both the adolescents and their parents were asked to fill out peer-validated questionnaires so that researchers can evaluate progress. “These groups were created based uniquely on clinical approach, meaning without the same selection or limitation criteria inherent in research

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projects. The groups are therefore very representative of what can be done in a classic therapeutic setting,” explained Dr. Fombonne.

The study results definitely back up this conclusion, as there was a discernible increase in patients’ social skills over the course of the sessions, an improvement that was maintained outside the training groups. This last point proves that behaviour improvement in these patients is not solely tied to the hospital environment. The training has also helped some of the adolescents reduce problems with excessive irritability or sensitivity.

<http://www.muhc.ca/media/news/?ItemID=27787>

<http://www.medicalnewstoday.com/articles/87642.php>

Starved child — NSW state of despair

Bob Buckley, 10/11/2007

The media has gone into a feeding frenzy over the story of a 7 year old girl (allegedly with autism) who died recently in NSW; allegedly of starvation.

Most criticism is directed at NSW DOCS and its minister but crucial systems have already failed by the time it becomes a problem for DOCS. Basic questions need to be asked of FaCSIA federally and DADHC in NSW about how the services provided for Shellay Ward met the requirements of the National Standards for Disability Services (1993) - [PDF \(85kb\)](#) | [RTF \(45kb\)](#).

I am not aware that autism can cause a 7 year old child to weigh just 9 kilograms (apparently the average weight of a 7 year old is 21 kg). Why was Shellay Ward not in hospital? Is part of the reason that health systems refuse to treat people with severe autism?

Hmmm. As I recall, around the last federal Budget the AMA advised the federal Health Department (DOHA) that people with autism do not need extended health checks, despite their being diagnosed with severe communication disorders (which means they have difficulty describing their symptoms). Of course, none of the DOHA bureaucrats knew enough to question this advice — despite A4 having highlighted the issue. So the AMA and the health system chose recently to deny people with autism effective access to basic health services that they may need.

Well that is discrimination. But Section 45 of the Disability Discrimination Act protects decisions like the one in the last Budget ... and all such acts of “lawful” discrimination by Government that deny people with autism essential services. Despite this being a clear breach of the UN Convention on the Rights of the Child, and several other relevant international treaties, the federal Attorney-General does not think this is an issue. The shadow Attorney-General is not interested in talking about it until after the election.

We asked for help, but so far lawyer organisations around the country are not interested in helping protect the human rights of Australian children with autism. And HREOC says human rights matters for children with autism relating to states are outside its jurisdiction.

Shellay Ward was 7 years of age ... the (bipartisan?) autism packages announced recently would not have helped her unless somehow a few days training for her school teacher would somehow enable her teacher to provide in her classroom the health care Shellay needed ... while teaching all the other students in the class. Oh, that’s right ... like many kids with ASD, Shellay did not go to school so that would not have helped.

A headline in the Sydney Morning Herald asks “How could this little girl have starved to death?” As I understand it the entire system is designed to deliver outcomes like this for children with autism.

The NSW Government learned nothing from the Dawes case several years ago despite clear advice from the Bench. Disability Ministers in NSW do not return calls about people with autism in desperate plights. And the NSW opposition is pretty ineffectual on these issues. I

guess these complex issues are just too hard for any of them to deal with. (I have not bothered trying to call the latest NSW minister or shadow minister ... the capacity of an unfunded advocacy groups is limited and our ability to chase state level politicians is minimal).

Will any of the planned inquiries get to the bottom of this? I doubt it.

Here are some links to more of the media cover ...

http://blacktown.yourguide.com.au/detail.asp?story_id=1083318

<http://www.news.com.au/dailytelegraph/story/0,22049,22717347-5006505,00.html>

<http://www.abc.net.au/news/stories/2007/11/06/2082640.htm>

<http://www.abc.net.au/news/stories/2007/11/07/2083646.htm>

<http://www.smh.com.au/news/national/how-could-this-little-girl-have-starved-to-death/2007/11/06/1194329224803.html>

<http://www.theage.com.au/news/national/9kg-autistic-child-7-found-dead-at-home/2007/11/06/1194329225797.html>

<http://www.smh.com.au/news/national/child-starves-to-death-in-her-bed/2007/11/06/1194118018891.html>

<http://www.smh.com.au/articles/2007/11/06/1194329224803.html>

<http://www.smh.com.au/news/national/starved-girls-sister-was-taken-from-her-family/2007/11/07/1194329318807.html>

<http://www.theage.com.au/news/national/sevenyearold-starves-to-death/2007/11/06/1194329221138.html>

<http://www.theage.com.au/news/NATIONAL/Probe-starts-into-childs-starvation/2007/11/06/1194118012256.html>

<http://www.theage.com.au/news/national/disturbing-story-behind-tragedy/2007/11/07/1194329319272.html>

<http://www.smh.com.au/news/NATIONAL/Starvation-victim-never-went-to-school/2007/11/07/1194329303047.html>

<http://news.ninemsn.com.au/article.aspx?id=64105>

<http://www.abc.net.au/news/stories/2007/09/06/2026328.htm>

Convenor's message

Dear member

There are two weeks to go in the election campaign. Will there be more policy on autism? I continue trying to work with relevant members of all parties on Autism/ASD policy (especially the major parties).

A number of A4 members have written to me with concerns that ALP policy on ASD remains unclear. While the \$190 million ("me too" for the ALP) is similar for the major parties, the ALP plan for six childcare centres is not documented. All we know is that one of their childcare centres will be in NW Tasmania (see

<http://www.abc.net.au/news/stories/2007/10/29/2072624.htm>).

I wish I could understand Labor in relation to ASD. For years their shadow ministers were reluctant to meet us. Frankly, they were ineffective in opposition in relation to autism/ASD. I understand federal Labor has limited capacity but A4 offers resources money cannot buy to help political leaders of any political persuasion to develop appropriate policy if they really are interested. Unless they show clearly before the election that they have a better understanding of the needs of people with ASD, we can only hope they will develop such an understanding if they win Government.

Labor's *National Platform and Constitution, Chapter Thirteen - Respecting Human Rights and a Fair Go for All* (see http://www.alp.org.au/platform/chapter_13.php) says

33. Labor is committed to real consultation with children and young people about issues affecting them as well as including parents, communities, community organisations and advocacy groups. Labor will pursue a positive and integrated agenda which recognises and values the strengths, contributions and resources of all young people.

The issue of ASD is testing their commitment "to real consultation". So far they are not doing well in respect of ASD-related consultation ... just as Labor does very poorly on this issue at the state level.

In the meantime, federal bureaucrats are getting on with implementing the ASD initiative (spending \$190 million) ... now bilateral policy. FaCSIA has recruited community members for their Implementation Advisory Group (IAG). The plan is to meet soon (showing the bureaucrats expect this will go ahead no matter what the election result). I accepted a position representing A4 on their IAG.

Please excuse my cynicism over stories like these:

- **Psychological Assistance For Children With Autism, Australia** see <http://www.medicalnewstoday.com/articles/84888.php>
- **Support For Autism Patients Welcome, Australia** see <http://www.medicalnewstoday.com/articles/84486.php>

Having tried for years to interest professional groups in ASD, one can but wonder whether their sudden and new found interest is purely pecuniary¹. A search of the APS website (<http://www.psychology.org.au>) for either "autism" or "asperger" found but one item: a dated piece of self-promotion (see <http://www.psychology.org.au/publications/inpsych/autism/>).

Many people with the most skills and experience with ASD in Australia do not meet membership criteria for organisations like the APS. Conversely, most APS members lack the training, skill and experience required to service people with ASD appropriately.

In the case of the AMA (see <http://www.ama.com.au/>) the search does find their recent news release and items from 2005 and 2003. In 2005, the AMA warned GPs ...

MMR and autism

GPs may encounter an increase in patient inquiries and concerns about the safety of the measles-mumps-rubella (MMR) vaccine in coming weeks. The AMA understands the ABC Four Corners program is running a story on Monday night about MMR and whether there is any evidence to support claims it can cause autism. GPs can prepare themselves for questions on this issue by reviewing the Immunisation Handbook at Appendix 4 (Commonly Asked Questions), section 3a(iii). The Handbook can be found at <http://www1.health.gov.au/immhandbook/>

This raises the interesting challenge: what qualifications and experience can/should we expect of people who treat people with ASD and supervise their programs? We cannot simply accept the completely incredible claims from these organisations that their members were trained to treat ASD.

Clearly, we cannot trust these organisations to regulate their members in relation to ASD. In the case of the AMA, there are plenty of GPs practicing who do not recognise ASD (see *Autism is life long* below for yet another recent example of delayed diagnosis ... reporting "a lack of knowledge of autism in health and education sectors produced a diagnosis at 10 [years of age]"), and some GPs deny ASD even exist. Many professionals were trained when PDD were on Axis II in the DSM-II or DSM-III. They lack the knowledge and experience of modern services and treatments that need to be provided under new ASD-related Medicare items. Some GPs and mental health workers were taught that there are no effective interventions for PDD/ASD: surely such people cannot suddenly be funded to guide and advise on programs for people with ASD.

¹ Relating to or involving money

In the case of the AMA, we note that their “experts” advised the Government in the last Federal Budget that people with ASD (unless they have an intellectual disability) must be excluded from Medicare items for extended health checkups. Could they be confusing the Hippocratic Oath with hypocritical oafs?

Basically, qualification issues needs to be sorted out by June 2008.

I found a recent discussion of inclusive education on the web interesting (**Thoughts About Inclusion, Special Ed and Loneliness** ... see <http://autism.about.com/b/a/257926.htm>). Clearly there are many stories of successful inclusion and many stories of failure. It is disgraceful that governments entrench such a practice in policy without any monitoring or credible research that gives evidence of effectiveness, let alone best practice.

Let me finish on a slightly positive note with a link to research headed **Study shows autism symptoms can improve into adulthood** ... see <http://www.news.wisc.edu/14167>. The item says

Like most people, individuals with developmental disabilities such as autism continue to grow and change over time, Shattuck explains: “Their development is not frozen in time and forever the same. That’s just not the case.”

Regards
Bob Buckley
Convenor

8/11/2007

In the media

ABC commentary on autism initiative

The ABC was the only media outlet that really covered the autism announcement.

- Labor pledges specialist autism centres see <http://www.abc.net.au/news/stories/2007/10/03/2049443.htm>
- Fed Govt and Labor announce funding for autistic children see <http://www.abc.net.au/am/content/2007/s2049508.htm>
- PM announces \$190m for children with autism see <http://www.abc.net.au/worldtoday/content/2007/s2049837.htm>
- Labor accused of copying autism policy see <http://www.abc.net.au/news/stories/2007/10/03/2049778.htm>
- Govt, Opposition announce autism packages see <http://www.abc.net.au/pm/content/2007/s2050334.htm> and <http://www.abc.net.au/news/stories/2007/10/03/2049522.htm>
- Family calls for better policies on autism treatment see <http://www.abc.net.au/news/stories/2007/10/03/2050347.htm>
- Autism packages 'ignore adults, adolescents' see <http://www.abc.net.au/news/stories/2007/10/05/2051619.htm>
- Political support for autism welcome as first step see <http://www.abc.net.au/rural/tas/content/2006/s2052050.htm> and <http://www.abc.net.au/rural/qld/content/2007/s2050979.htm>

Tasmania: Inquiry to improve children’s care

Posted Tue Oct 23, 2007 7:00pm AEST

The Health Minister Lara Giddings says an inquiry into the number of children living in disability respite services will identify areas that can be improved.

Ms Giddings says Tasmania's Commissioner for Children, Paul Mason will look at the situation of children spending long periods in respite centres.

It was revealed last week a seven year old autistic boy had spent most of his life being raised by rostered carers in a respite facility.

Ms Giddings told Parliament seven children had been cared for on a long term basis in respite facilities over the past year and two children are permanently accommodated.

She says Mr Mason will review Government policy and provide advice in relation to the care of such children in the future.

"I hope that through the advice the commissioner for children can provide me, I will be able to provide further confidence to this house that we are indeed doing everything we can to look after these children, who often have been placed in our care by parents who feel they cannot look after the child themselves," said Ms Giddings.

<http://www.abc.net.au/news/stories/2007/09/06/2026328.htm>

<http://www.abc.net.au/news/stories/2007/10/18/2063459.htm>

<http://www.abc.net.au/news/stories/2007/10/19/2064754.htm>

<http://www.abc.net.au/news/stories/2007/10/19/2064070.htm>

<http://www.abc.net.au/news/stories/2007/10/19/2063633.htm>

<http://www.abc.net.au/news/stories/2007/10/23/2068204.htm>

<http://www.abc.net.au/news/stories/2007/10/29/2072624.htm>

Cash pledge for autism

Tim Vainoras

22Oct07

AFTER decades of neglect, political parties are starting to throw money at autism services in the lead-up to the federal election, a leading autism centre says. *Read more at*

http://www.heidelbergleader.com.au/article/2007/10/22/24232_hbv_news.html

Politicians hopeless on disabilities and carers

A meeting/forum in Melbourne produced quite a bit of media ... especially in The Age ...

- <http://www.theage.com.au/news/federalection2007news/insulted-carers-jeer-brough/2007/10/30/1193618865325.html>
- <http://www.theage.com.au/news/federalection2007news/labor-and-brough-roughed-up-by-carers/2007/10/30/1193618887013.html>
- <http://www.theage.com.au/news/NATIONAL/Disability-sector-needs-a-boost--Brough/2007/10/30/1193618852779.html>

What a "choice"

MINISTER Mal Brough's comment (*The Age*, 31/10), that carers "choose" to care for their disabled kin is stated in sheer ignorance of the facts. To "choose" clearly gives the impression that one has alternatives available. This, as the minister knows, is not the case.

As secretary of Frankston/Peninsula Carers Inc, I can assure your readers that our members, each of whom cares for a family member with varying degrees of intellectual and physical disability, does so as a course of must and love. These are the people who forgo their own future retirement, their health, financial stability and the way of life that others take for granted. There are no choices, there are no alternatives.

Unpaid caring labour by more than 2 million Australian carers has saved the Government billions of dollars over the years. Band-Aid solutions to rectify critical situations as they arise does not provide a solution for the long term.

Karl Hell, Crib Point

Autism is life-long

IF LABOR and Mal Brough thought it was a bit tough being roughed up by carers, then step into my family's shoes! Our son, aged 13, is autistic and on medication for anxiety and depression. A lack of knowledge of autism in health and education sectors produced a diagnosis at 10.

We funded his diagnosis; we research, design and implement ad hoc therapy programs and perform the specialised work of occupational, speech and behaviour therapists. There are limited programs for children older than six, let alone those older than 10. We understand the importance of early intervention.

We will see no benefit from the two major parties' policies on autism regardless of the election result. Our son is not a pre-schooler. Are Labor and the Coalition suggesting we enrol him in their proposed autism programs to play catch up with three to six-year-olds?

Wake up policymakers! Autism, like most disabilities, is life-long. Our son has complex needs. He no longer attends school; for safety reasons we have been forced to home-school him. Minister, this is not something we've chosen to do.

The proposed funding package of both major parties gives me no hope for now or the future. That is something that is truly rough!

Lisa Thomas, Highett

The Age 2/11/07

The trouble with Harry

On the ABC Okham's Razor ...

Science teacher **Dr Berry Billingsley** from Windsor in the UK talks about her life with Harry, her nine-year-old son who has Asperger's syndrome.

<http://www.abc.net.au/rn/ockhamsrazor/stories/2007/2071202.htm>

28 October 2007

McCarthy Calls Carrey 'Autism Whisperer'

NEW YORK — Jenny McCarthy worried about finding a good man after her son, Evan, was diagnosed with autism two years ago. Then Jim Carrey came along. "Beyond doubt it was written in the stars that Jim and Evan were a pair," the 34-year-old actress tells People magazine in its Oct. 1 issue.

"He's actually helped Evan get past some obstacles I couldn't. I sometimes call him the autism whisperer. He speaks a language Evan understands, and Evan feels safe with him."

McCarthy and Carrey, 45, went public with their romance last year. Though she's in love, McCarthy has no plans to marry the twice-divorced actor.

"There will be no certificate," she says. "It goes far deeper than that. Jim came into our life with an open heart and open arms. He's learned a lot about autism. He listens. The power of listening. It can move mountains."

McCarthy and film director John Asher filed for divorce in August 2005, after six years of marriage. Earlier that year, Evan, now 5, was diagnosed with autism.

McCarthy, who starred on MTV's "Singled Out," details Evan's progress in her new book,



“Louder Than Words: A Mother's Journey in Healing Autism.”

She says Carrey was curious about Evan _ in a good way. But she was nervous about introducing them.

“He was intrigued,” she says. “He asked questions. Still, it took me about a few months to bring Evan over.”

September 20, 2007

Autism screening urged for toddlers by age 2

Pediatricians group says early therapy can lessen disorder's severity

CHICAGO - The country's leading pediatricians group is making its strongest push yet to have all children screened for autism twice by age 2, warning of symptoms such as babies who don't babble at 9 months and 1-year-olds who don't point to toys. ... see <http://www.msnbc.msn.com/id/21515865/>

If you have broadband, you might like to look at the item from US TV (there is a short ad. first ... try to ignore it) <http://video.msn.com/?mkt=en-us&brand=msnbc&fg=rss&vid=0d75b5b3-4065-491c-b51f-1844a5dfe7c5&from=05>

This lead to a short story on national Prime news with two quick grabs of Bob ...some of you may have seen it.

A4 Website: time for change?

A4's website is crucial to our success. It is where people find out about A4 and communicate with us.

So far, it has been a relatively static and stable website. But now may be the time to create a community website for people with ASD, their families, their carers and other relevant groups.

The website can continue to provide basic factual information. But it can be much more. It can provide a database of relevant services in the regions around the country. We can have online forum discussions of topics that arise so A4 members have a more immediate say in our organisation.

Can we establish a group of people around the country to help build an online community? An initial thought is that we need three types of people:

1. moderators for forum/discussion group and website content. Mostly, these people would try to keep discussions “on subject” ...
2. content creators for the website ... especially for things like a “frequently asked questions” section, perhaps for a services database and other items of useful information.
3. website technicians to maintain the technical part of the website.

Since A4 started, Cris Ruhr has managed our website. A4 owes him a huge thanks for his work over the years. Cris is prepared to continue supporting our website if we decide to continue as before. But if we decide to change, Cris and I cannot do this on our own ... we would need a bigger group to make it work.

I already contacted the people who registered an interest in the website in their membership information. But if you are interested in helping with A4's website, please email me at cnvnr@a4.org.au. If you know anyone interested in helping with our website, please get them to email me.

Or if you think this is a bad idea tell us why.

Link: ARI Biomedical Survey Analysis

This Internet program allows parents to utilize ARI's treatment database survey, the largest in the world, to help determine what treatments to consider trying (or possibly avoiding) for their children. After a parent rates how a child responded to one to four treatments in the past, the program searches ARI's treatment database (more than 25,000 records) and then summarizes how other children who responded in a similar manner to these treatments responded to other treatments. (For example: if a child responded well to melatonin, the program will provide a list of additional treatments that benefited children who also responded well to melatonin.) There is no charge to use this program. ...

See <http://www.autism.com/biomedicalsurveyanalysis/index.html>

A4 Contacts

A4 is a grassroots organisation. All A4 activity, such as publishing the Updates (newsletters), is done by volunteers. Please understand that A4 volunteers may have no training or qualifications for their various roles. They do the best they can for people with ASD, their families and associates. A4 welcomes assistance and constructive criticism.

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Editing: normally Juanita and Vicki ... but Bob Buckley did this one.

Reporting: vacancies in all states.

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

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