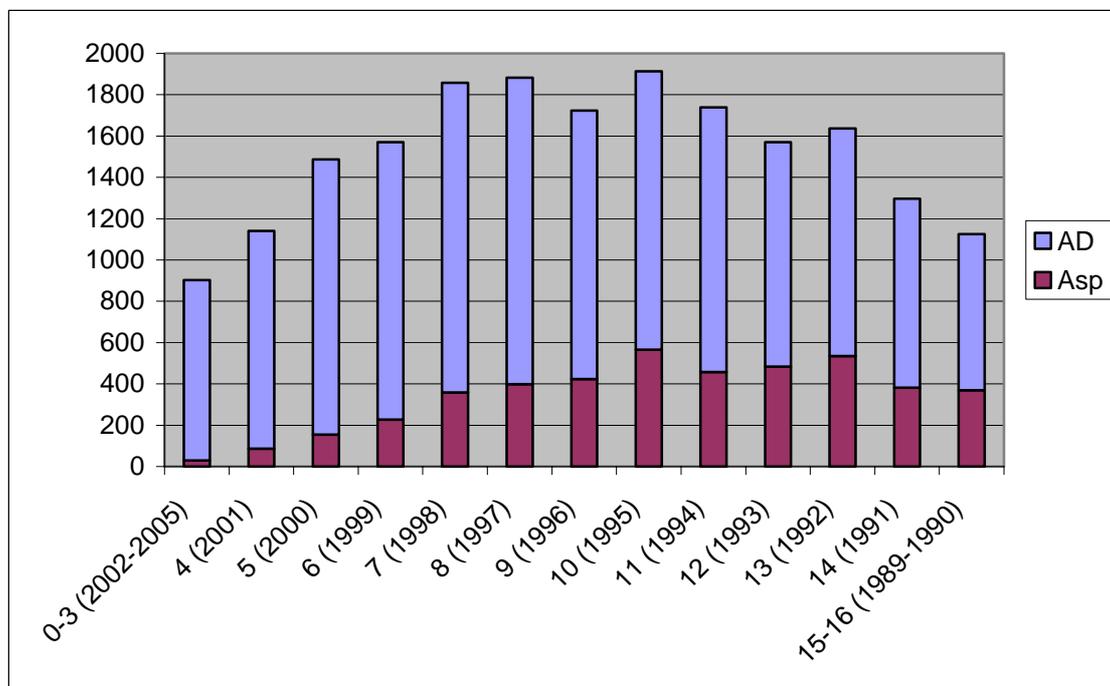


## Data from Centrelink on Autism Spectrum Disorders

**Bob Buckley 20/10/2006**

Recently, The Hon. John Cobb MP, federal Minister for Community Services, gave A4 data showing 19,844 children with either Autistic Disorder or Asperger's Disorder had carers who received Carer's Allowance at June 2006. Figure 1 shows an age/birth year breakdown.



### Inside this Issue

Data from Centrelink on Autism Spectrum Disorders	1
Convenor's message	3
PDD-NOS Diagnosis in Australia	6
South Australia's good report card on ASD ...	9
Passing of Dr Bernard Rimland	9
Conference Paper from South Africa	10
Industrial Chemicals May Be a Cause of Autism	16
Temporary email addresses	17
A4 Contacts	17

### Disclaimer

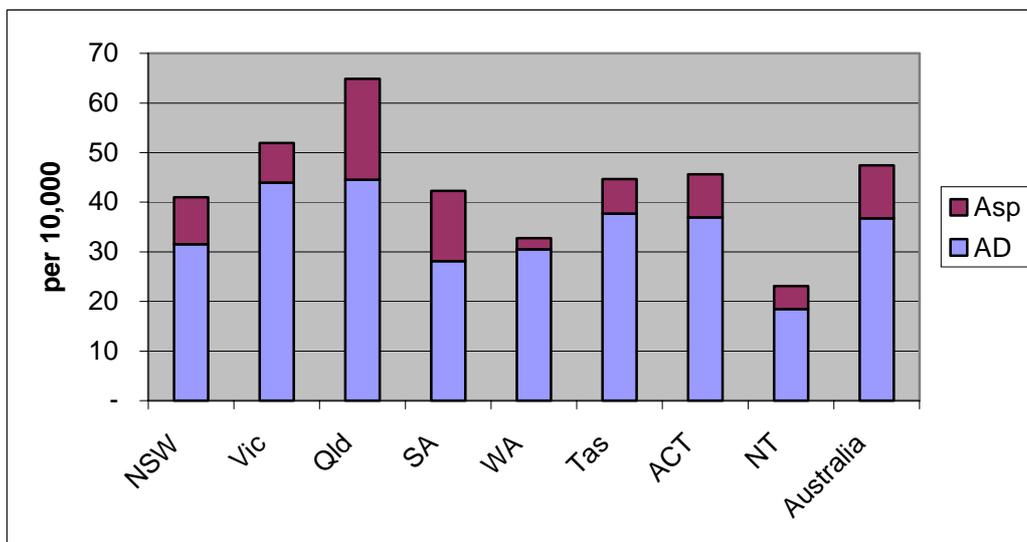
While we have made every effort to ensure that information is free from error, A4 does not warrant the accuracy, adequacy or completeness of the information, graphics and materials in the A4 Update. A4 does not guarantee that A4 Updates will be free from viruses.

A4 is not responsible for the results of any action taken or not taken on the basis of any information in the A4 Update, nor for any error or omission in that information. A4 expressly disclaims all and any liability and responsibility in respect of anything done consequent on the whole or any part of the information in the A4 Update. A4 shall not be liable for any loss, damage, liability, expense, cost or personal injury, whether direct or indirect, consequential or incidental, which you suffer, incur or are liable for, howsoever caused (whether due to A4's negligence or otherwise), arising from or in connection with your use of A4 Updates.

These national data suggest:

- diagnosis rate rising until reaching a plateau for children born since the mid-1990s.
- nationally, more than 67% (2/3) of children diagnosed with Autistic Disorder are diagnosed before age 4 years (there are 1054 at age 4 and a maximum of 1499 in any year).
- people with Asperger's Disorder are given their diagnosis later (at an older age) compared to people diagnosed with Autistic Disorder.
- the number of people diagnosed with Asperger's Disorder as a proportion of those diagnosed with an Autism Spectrum Disorder approaches 33% when they leave school, though this varies between states.

The Minister provided a breakdown by state. These data are presented in this figure.



Please be careful interpreting this information. This data does not show the prevalence of ASD, it shows the number of people receiving Carer's Allowance. There are many people in the age range who have an ASD but have not yet been diagnosed.

The Minister did not provide data for the other PDD categories. In particular, the Minister's figure did not show Carer's Allowance for people diagnosed with PDD-NOS. I expect those numbers are small but would be very interested to see what they are.

People with PDD-NOS could bring the rate in WA closer to the level shown for South Australia. People with PDD-NOS encounter a more complex process to qualify for Carer's Allowance.

There is also the issue of uptake: not everyone who has ASD received Carer Allowance. The Autism SA Annual Report 2005/6<sup>1</sup> says

*There are nearly 1800 students with an Autism Spectrum Disorder attending State Schools, Catholic Schools and Independent Schools ... (page 7)*

But there are just 1,300 people who receive Carer Allowance. While the number in schools and the number receiving Carer Allowance are not expected to be the same, there could be an expectation that the numbers would be similar. This may indicate that Carer Allowance has less than complete uptake and does not reflect the number of people with ASD in the community.

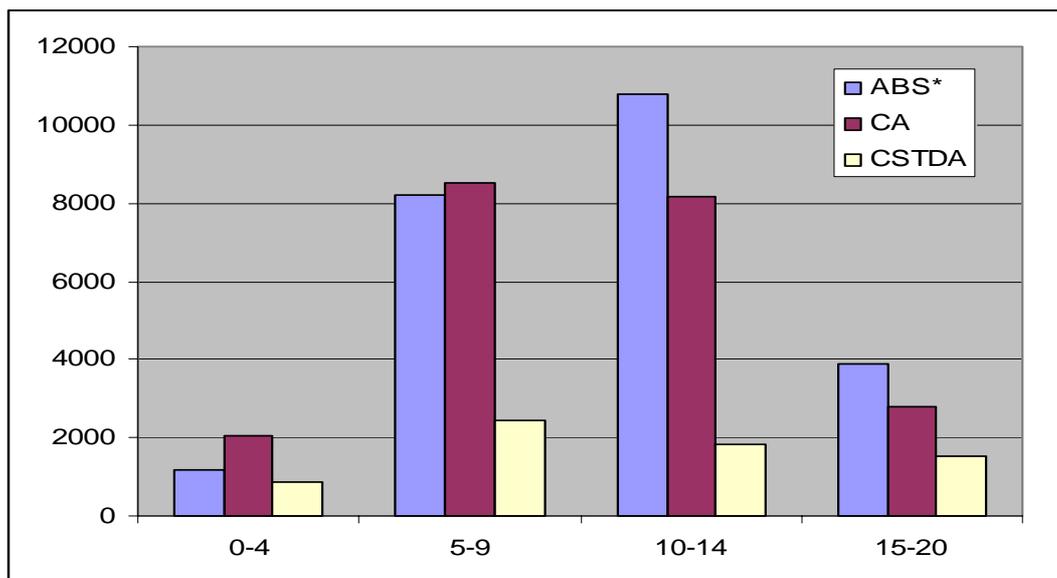
The level of Carer Allowance in Queensland is almost double the rate in Western Australia. This level of variability should concern governments: the reasons behind this variability are not likely to be positive.

The following graph shows data from two other sources:

- the Australian Bureau of Statistic (ABS) Survey of Disability, Ageing and Carers (SDAC) in 2003; and

<sup>1</sup> <http://www.autismsa.org.au/pdf/AR%2006.pdf>

- the AIHW website showing people who receive services funded through the Commonwealth State Territory Disability Agreement CSTDA, for people whose “primary” disability is autism.



The number of people with autism in the various age groups will have increased since 2003<sup>2</sup>. However, this picture suggests that most people with an autism spectrum disorder (though not all) benefit from the Carer Allowance. It also suggests most people with autism do not receive services funded through the CSTDA. Note that Carer’s Allowance data is extrapolated to 20 years of age.

The low level of CSTDA services is a major concern because the Australian Institute of Health and Welfare (AIHW) reports that people with ASD are the most likely to experience severe or profound disability; the data confirms that people with ASD have a very high need for services yet the data shows they are not receiving the services.

## Convenor’s message

Dear A4 member

I am upset ... and I am going to tell you why.

Firstly, Mr Pitt, Qld Disability Minister upset me. *A Current Affair* showed convincing evidence that Mr Pitt, Qld Disability Minister, lied about his dealings with the media and about people with autism.

He is disgraceful. Instead of an apology, he attacked personally the people who spoke up. Mr Pitt shows he regards respite as an adequate response to chronic challenging behaviour. No Mr Pitt, respite is utterly and pathetically insufficient. This Disability Minister has clearly failed in his responsibility for his state’s ensuring the rights of children disabled by their autism to receive treatment and rehabilitation. A meagre service made up of a bit of respite is a profoundly inadequate response.

Mr Pitt has a track record. He told the Queensland Parliament, back in May 2004 (during Autism Awareness Week) that 10% of Queenslanders have autism. Ten percent is about 360,000 Queenslanders diagnosed with an autism spectrum disorder. No way! Minister Pitt is sublimely clueless.

We are supposed to respect politicians and refer to them as “The Honourable ...”, but his conduct and ignorance are not honourable. Mr Pitt squandered his opportunity for my respect.

<sup>2</sup> the increase from 1998 to 2003 was 43%, which is very high. Data sources such as the WA Autism Register and diagnosis rates from other states suggest the growth in ASD prevalence from 2003 to 2006 has not been as large ... perhaps in the 10-15% range nationally.

The reporter on *A Current Affair* identifies several state Ministers who have not responded to questions about services for children with autism: Ministers who are absent without leave. They were also absent from the SBS Insight Forum a few months ago. The Shadow Ministers are mostly absent as well.

Ironically, the media depicted the “Ministers for dodging Disability Issues” using their pictures on empty chairs,



like the image A4 used to represent people with ASD in our September 2004 Autism Awareness Event in front of Parliament House (see <http://www.a4.org.au/awarenessevent/index.htm>):



Should I be outraged, or inclusive of these Ministers with their profound moral and credibility impairments? Hmm ... I decided I am outraged (the Disability Discrimination Act 1992 does not recognise moral and credibility impairments). And the leather chairs really highlight the equity issues.

Secondly, the media upsets me when it presents purely negative image of autism. The media is increasingly about making money and less about journalism and informing the community. It seems media owners and/or operators want the most dramatic footage they can get, and negative extremes provide the most dramatic stories and images.

So the media portrays autism with images of the most challenging behaviour. These are important images and I thank the courageous families who confronted governments and the community on *A Current Affair* in early October with their reality.

But a balanced media would also depict positive aspects of autism in the community. It would make room for some of the positive stories relating to autism.

I think what upset me the most, was the end of the show, when the presenter referred families whose children have developed severe challenging behaviour to the autism association in their state. This is unhelpful and annoying, possibly patronising and insulting, because the families have already been there and done that. For various reasons, they did not get the services and support they need or they would not be in the situation.

Autism politic in Australia precludes one from mentioning any specific approach. So when it comes to challenging behaviour associated with autism, some state associations cannot bring themselves to mention, let alone provide, services of the particular type that is universally recognised treatment for challenging behaviour (for example see <http://www.cddh.monash.org/assets/chabev.pdf> which shows the Victorian government sets up advisors then ignores the advice given in relation to autism).

Thirdly, Brendan O'Reilly upset me. Soon after the Forum, the NSW Coroner released finding on the death of Jason Dawes<sup>3</sup> (it seems to be particularly difficult for members of the public to get their hands on this document). The press reports<sup>4</sup> ...

---

<sup>3</sup> see <http://www.theage.com.au/articles/2006/10/13/1160246321278.html> and <http://www.news.com.au/story/0,23599,20574029-1702.00.html>

*The director-general of the Department of Ageing, Disability and Home Care (DADHC), Brendan O'Reilly, said the findings and recommendations would be examined, but a number of government initiatives in recent years would go some way to addressing the matters raised.*

Mr O'Reilly said the Government's \$1.3 billion 10-year plan for disability services would increase early intervention and support for families with a child with a disability.

A Current Affairs Forum on Autism shows the NSW Government learned very little from the death of Jason Dawes: it clearly shows "government initiatives in recent years" do not address the needs of children with autism and their families. I am deeply disappointed by the NSW Government's delusions and deceptions over the issue of autism. The NSW Government's "consideration" (or clear lack thereof) of the Magistrate's comments in the matter of Jason Dawes made no discernible difference.

Recently, Mr O'Reilly wrote to me grossly understating the number of children in NSW affected by autism: Mr O'Reilly says just 1.7 per 10,000 are affected while over 41 per 10,000 receive Carer Allowance in NSW (see below). The NSW Government's plans for children with autism are based on delusions. The Director-General and the Minister refuse to recognise the magnitude of the problem facing the NSW community. Government inaction imposes a massive burden on the community, especially on the families affected by autism.

International and domestic experts, including those from NSW hospitals, say children with autism need intensive autism-specific early intervention ... around 20 hours per week minimum autism-specific early intervention to make the improvements they need. Mr O'Reilly's Department neither provides nor funds early intervention for children with autism that is autism-specific and sufficiently intensive. A few children with autism spend months or years on waiting lists for an utterly inadequate couple of hours per week for just a few weeks. A few brave parents showed the outcomes of this system on national television last week.

The NSW "Government's \$1.3 billion 10-year plan for disability services" does not include plans for appropriate intensive early intervention for children with autism, and certainly not for the number of children being diagnosed with autism in NSW. In this context, Mr O'Reilly is **misleading and especially cruel** to gloat over the NSW Government's 10-year plan to increase funding for disabilities generally while denying most children with autism appropriate evidence-based early intervention that is effective in treating a child's autism.

AIHW publications show that people with autism have the highest rate of severe or profound disability. People with autism are often described as having high and complex needs. This means it is difficult to access and manage a suitable combination of services. People with autism need coordinated services from numerous agencies. Typically they also need the services of a good caseworker.

In NSW, DADHC policy does not provide caseworkers unless the person has an intellectual disability. Most people with autism do not have "intellectual disability", so DADHC policy denies effective services to many people with severe or profound disability and complex needs due to their autism: that is, the people who most need caseworkers. Policies and practices like this make it impossible to get even an adequate service for autism in NSW.

Next, I am upset that Mr Christopher Pyne MP, Secretary for Health and Ageing seems to have forgotten about his commitment to a "substantial initiative" for autism ... and his staff will not respond to my attempts to communicate with him or them.

Next, I was upset to hear federal and state politicians discussing (arguing over) indexation of disability funding in the Committee hearings for the CSTDA Inquiry. Such a discussion would be relevant were services at or very near the level of need ... and if the level of disability in the community was constant.

Neither of these is the case. So this discussion shows governments at both levels plan ongoing refusal to recognise and address massive unmet need in the disability sector. This particularly affects people with autism spectrum disorders where the number of people continues to grow at an alarming rate. The result of growth in the context of indexed funding is that the level of service available for an individual with an autism spectrum disorder decreases significantly as time goes along.

---

<sup>4</sup> See <http://www.theaustralian.news.com.au/story/0,20867,20574918-5006784,00.html> and <http://www.smh.com.au/articles/2006/10/13/1160246332494.html>

Next, I am upset that The Hon Mal Brough MP, Minister for Families, Community Services and Indigenous Affairs, created yet another disability advisory body that has no representation for people with ASD.

I spoke with his advisor during the month. This Minister has been in the position for approaching a year, yet his Departmental staff members have not advised him of any issues relating to ASD.

Next, on the 23/10/2006 A4 received notice of a conference<sup>5</sup> entitled “Science Experts and the Courts” being run on the 4/11/2006. The topics include:

**ADHD, Asperger’s Syndrome & Autistic Spectrum Disorders in the Courts**

Judicial officers increasingly are confronting claims that ADHD and autistic spectrum disorders should affect decisions by courts in adult criminal matters, in child protection matters and in family law matters. What are the symptoms? Should a court have regard to the conditions as factors in cases? What strategies exist to manage these conditions? What are the differing views on the usefulness of treatment or support?

and

**Professionals in the witness box**

The reliance on expert evidence has many benefits for courts. What are the difficulties for experts in giving evidence in courts? How can a person called as an expert witness best prepare for that role? Should the courts be wary of “hindsight bias” when assessing the evidence of one professional about the actions of another (e.g. the potential for a medical expert to retrospectively simplify, trivialise or criticise the actions of a treating medical expert).

To end on a high note ... I was pleased with the reception I received from the Senate Community Affairs Committee when I spoke to them about the submissions to their CSTDA Inquiry from A4 and from me.

Whoops! It looks like I’ve waffled on far too long. I’ll look for more positive material for my next message.

Regards  
Bob Buckley  
25/10/2006

## **PDD-NOS Diagnosis in Australia**

**Bob Buckley, 22/10/2006**

The DSM-IV describes a number of disorders under the label Pervasive Developmental Disorders (PDD). The introduction to the section starts out by saying

*Pervasive Developmental Disorders are characterized by severe and pervasive impairment ...*

In other words, a person can be diagnosed with these disorders if they experience severe or profound impairment, if their disorder pervades or permeates the person (presumably their lives, how they behave) and if they meet the other specific criteria. People do not have episodes of a PDD; nor does it just affect some part of their lifestyle. PDD affects everything.

In many cases, the term Autism Spectrum Disorder is used instead of Pervasive Developmental Disorder.

The two main PDD subtypes are Autistic Disorder and Asperger’s Disorder. The other specific disorders listed in the DSM-IV are Rett’s Disorder and Childhood Disintegrative Disorder. In the future, Rett’s Disorder may disappear from the DSM-IV and follow Fragile-X into a different group of conditions where, unlike PDD at this time, the cause is known (but people with these conditions can also meet the diagnostic criteria for a PDD).

---

<sup>5</sup> see <http://www.njca.com.au/programs/Science%20and%20courts/Science%20&%20Courts.asp>

Then at the end of the section describing PDD in the DSM-IV, there is a “catch-all” headed *Pervasive Developmental Disorder Not Otherwise Specified (Including Atypical Autism)*. The usual shorthand is PDD-NOS. Clinicians can use the PDD-NOS category to label “severe and pervasive impairment” that has features of autism and does not meet the criteria for any of the specific conditions. Note that the criteria still require “severe and pervasive impairment”, just as it is for all the other specific diagnostic categories in the section.

The WA Autism Register report<sup>6</sup> for 2004 says 12% of ASD diagnoses in Western Australia are for PDD-NOS which is double the rate of diagnosis of Asperger’s Disorder in that state.

The story is very different in South Australia. The South Australian government funds the diagnosis of “autism” and Asperger’s. It does not fund the diagnosis of PDD-NOS. A clinician will not be paid for an Assessment that results in the diagnosis of PDD-NOS. Service providers are not funded by the SA government for services relating to PDD-NOS. The result may be that clinicians diagnose Atypical Autism, a category from the ICD-10 (the alternative to the DSM-IV developed by the World Health Organization), or just “autism” rather than PDD-NOS so the diagnostic label fits somehow into an “autism” category.

Clearly, there are massive differences between the states in the diagnosis and subsequent provision of services for people with (or apparently without) PDD-NOS.

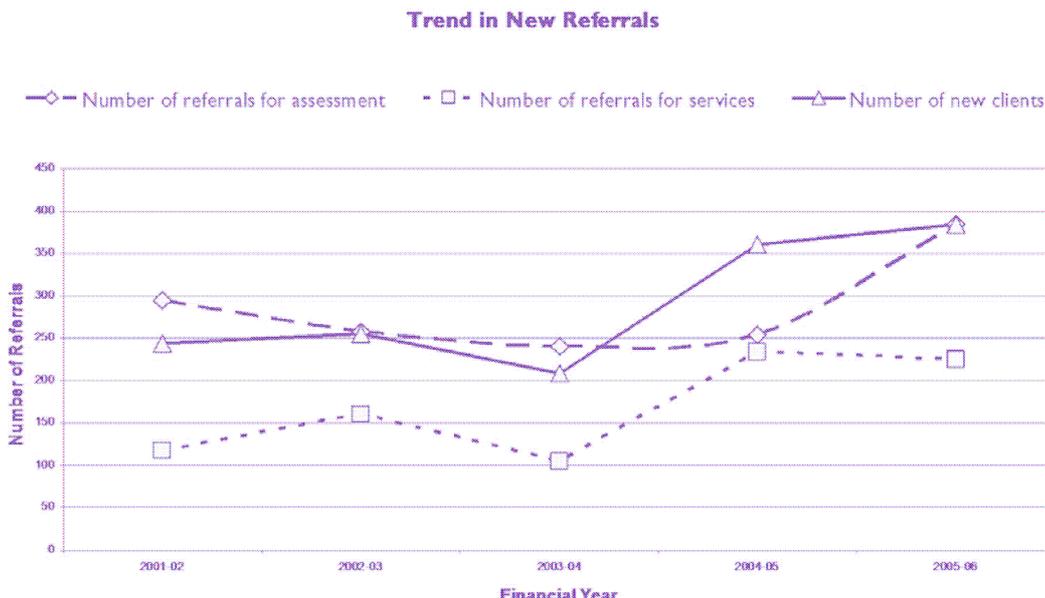
At the federal level, “Autistic Disorder” and “Asperger’s Disorder” qualify automatically for Carer Allowance. PDD-NOS does not, despite being a “severe and pervasive impairment”.

Issues relating to PDD-NOS have not really been raised with A4. In the circumstances, it seems unlikely there are no issues. It seems more likely that either people with PDD-NOS do not regard it as part of the autism spectrum or they obtain an autism diagnosis of some kind from another provider.

## South Australia’s good report card on ASD

**Bob Buckley, 20/10/2006**

There are recent reports of a big jump in the numbers of referrals for ASD assessment and in actual diagnoses in South Australia<sup>7</sup>. The following figure from the Autism SA Annual Report 2005/6<sup>8</sup> shows a short history of referrals and diagnosis in South Australia.

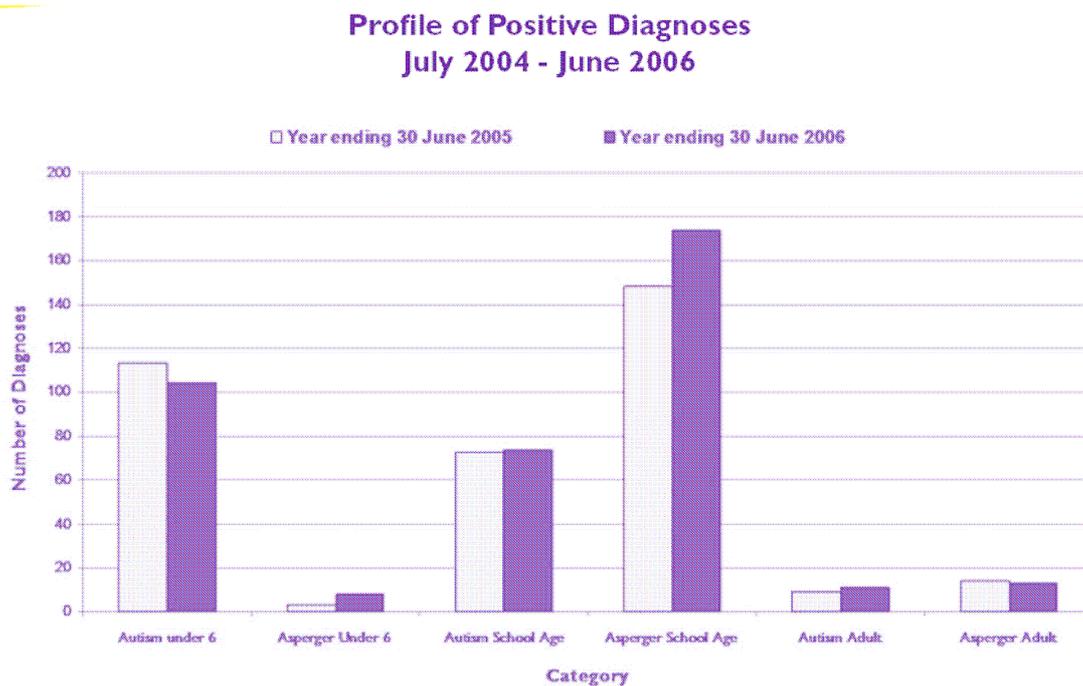


<sup>6</sup> <http://autismwa.org.au/2004annualreport.pdf>

<sup>7</sup> <http://www.news.com.au/adelaidenow/story/0,22606,20514382-5006301,00.html>

<sup>8</sup> <http://www.autismsa.org.au/pdf/AR%2006.pdf>

The “number of new clients” is close to the number of diagnoses in SA. New clients are those people Autism SA diagnoses and the people diagnosed by other agencies and referred to Autism SA for services. The following figure shows the breakdown of diagnoses by age group and ASD subtype for the last two financial years.



Most people with Autistic Disorder are diagnosed before school age, though quite a few are diagnosed at school age. People with Asperger’s Disorder tend to be diagnosed after they reach school age.

Overall, there is a similar number of people diagnosed with Autistic Disorder and Asperger’s Disorder. This differs from other states and territories where Autistic Disorder has a high proportion of diagnoses. Western Australia is the opposite extreme: the WA Autism Register report<sup>9</sup> for 2004 where PDD-NOS is 12% of diagnoses and Asperger’s Disorder is just 6%. These figures suggest massive variability in diagnostic practice between states.

There are no diagnoses of PDD-NOS reported in South Australia. This is probably because the South Australian Government does not pay for a PDD-NOS diagnosis and Autism SA is not funded to provide support. A diagnosis of PDD-NOS would have no benefit in the form of services. This issue is discussed in a separate item.

### *South Australia’s correctional services may lead the nation with its awareness of ASD*

South Australia’s correctional services may lead the nation with its awareness of ASD. The Autism SA 2005-06 Annual Report also observes (page 10) ...

A notable increase in referral sources this year were those coming from the correctional services system – both for adults currently in a correctional setting and those awaiting trial.

It is a serious concern that people who may have ASD may be over-represented in “correctional settings”. It is good that the needs of those who have arrived at this situation are being recognised and steps are being taken to get them the services and support they may need. The challenge for the community is achieve equitable outcomes for people with ASD, which means in part that people with ASD are not over-represented in correctional settings.

<sup>9</sup> <http://autismwa.org.au/2004annualreport.pdf>

Autism South Australia's 2004-05 Annual report contains the following commitment from the President (page 4)...

...by June 2008, there is to be a waiting time of no more than three months for a diagnostic assessment and there will be fifteen to twenty hours of support and/or intervention each week for children in the early development program.

While it would be ideal that a referral lead immediately into a diagnostic process, this may be a reasonable delay for some people referred for Asperger's assessment when so many are being referred in a relative small jurisdiction.

Autism SA is to be commended for these goals. To our knowledge, Autism SA is the only state-funded service aiming to provide service at the level national and international experts in the treatment of ASD recommend<sup>10</sup>. South Australia has the only state service that has adopted and published these laudable goals.

*Autism SA is the only state-funded service aiming to provide service at the level national and international experts in the treatment of ASD recommend*

The latest 2005-06 report says (page 6) ...

#### **Strategic Directions**

We continue to work towards our main objective from Autism SA's Strategic Plan of "ensuring that 15 hours of support and/or intervention is provided each week" for children in the Early Development Program by 2008. The constraints of funding arrangements clearly restrict our ability to achieve this goal. However, extension of the consultancy program and changes to the staffing mix within the program has seen some progress being made. Further, relationships with the Flinders University Early Intervention Research Program have been enhanced with a view to future collaboration.

The goal of having an option of a minimum of 15 hours per week of intervention or support is on-going, though mention of twenty hours disappeared (while Australian experts suggest 15 hours minimum may be sufficient, international experts suggest a 20 minimum). Government policy, support and funding constrain these goals and their achievement. These goals will not be achieved if the community in South Australia does not convince its government that they are important goals.

It would be good to see Autism SA publish the level of service it actually delivers. And we would be interested to hear directly from clients. Do services have the form and intensity their children require in their early years?

*Families ... must ... make sure their government shares this goal for children diagnosed with ASD*

This is not a time to rest: quite the reverse. Families of children with ASD in South Australia must get behind their association and Flinders University to make sure their government shares this goal for children diagnosed with ASD. You cannot afford to leave lobbying to service providers: they are not funded for it.

## **Passing of Dr Bernard Rimland**

Sadly, on November 21, 2006, a man seen by many as a champion and giant in the Autism world passed away at the age of 78. For over forty years, Dr. Bernard Rimland fought to bring

---

<sup>10</sup> J. Wray, N. Silove & H. Knott, (Apr 2005) *Language disorders and autism* MJA, **182**:7, pp354-360 available online at [http://www.mja.com.au/public/issues/182\\_07\\_040405/wra10330\\_fm.html](http://www.mja.com.au/public/issues/182_07_040405/wra10330_fm.html)

hope and help to children with Autism all over the world. Like many of us, his involvement with Autism began with his need to help his own child.

He began his work in the 1960's challenging the flawed notion that parents were somehow responsible for their children's Autism. He wrote, *Infantile Autism: The Syndrome and Its Implications for a Neural Theory of Behavior*, which provided powerful evidence that Autism was a biological disorder and that parents were in no way to blame for their child's Autism. During this time he also formed the National Society for Autistic Children (NSAC), now known as the Autism Society of America (ASA). This group provided parents with a forum where they could receive moral support and practical advice regarding the efficacy of therapies being used.

His involvement with the ASA allowed Dr. Rimland to promote therapies to parents as a way to help educate their child with Autism. Dr. Rimland also sought to address the biological foundations of Autism by starting the Autism Research Institute (ARI) in order to create a worldwide research center and clearinghouse for biomedical treatments. By listening to the parents he was able to follow their lead and investigate many promising biological interventions. ARI also promoted many biomedical treatments which were found to be very effective by parents.

He also sought to bring together the world's leading researchers in different fields to create a state-of-the-art treatment plan for Autism. This worldwide movement has been instrumental in organizing conferences and major research projects. As editor of the Autism Research Review International, now in its twentieth year, he provided parents and professionals from all over the world with crucial information about state-of-the-art treatments and research. Many in the international Autism/ASD community will continue to benefit from his enormous contribution. His presence will be greatly missed.

## Conference Paper from South Africa

"Providing opportunities for the development and maintenance of friendship and life skills to girls with autism spectrum disorder: A qualitative analysis".

Katharine Annear

BAppSc(DisStud) M.A.I.P.C.

### Introduction

*"Children feel accepted to the extent that they believe that they are valued for who they are and not under coercion to become a new, different person."* (Asher, Parker and Walker 1996)

This paper briefly explores the provision opportunities for the development and maintenance of friendship and life skills to girls with an autism spectrum disorder. The programs described have been developed by the author over a period of three years and have provided opportunities to 35 girls aged between eight and fourteen years. A best practice framework was considered when developing the programs and tools and activities are explored in relation

to this framework. A qualitative evaluation of these programs was conducted in July 2006 and the results are explored.

## Rationale

Girls with Autism and Asperger syndrome are a minority population within the spectrum of Autism; the ratio being four males diagnosed to every female (Ehlers and Gillberg 1993). As a result of this imbalance in the prevalence of these conditions much of the literature, research and intervention strategies address the needs of the male with Autism Spectrum Disorder. A brief review of the literature yields only a handful of articles addressing the profiles and needs of females with Autism Spectrum Disorder (see Attwood 1999, Kopp and Gillberg 1992). Females with ASD present with a unique behavioural phenotype that differs from males (Kopp and Gillberg 1992) therefore may benefit from program design that addresses their unique needs.

The personal and professional experiences of the author reveal that support for girls with Autism Spectrum Disorder should address the core deficits experienced and consider unique approaches to issues such as self esteem, identity, body image, sexuality and dealing with the dynamics of female friendship.

Within this service interventions and skill building programs designed for the male population have often proven to be unsuccessful when working with females on the spectrum. Furthermore, it seems that the core deficits experienced by a person with ASD leave females particularly vulnerable to harassment, abuse and exploitation within society. "Co-existing with the diagnostic difficulties, are other factors. In our culture, women are objectified in attitudes and media. The vulnerability this creates for all women is exponentially increased for women on the spectrum whose inherent social naiveté' interferes with social interaction." (Gassner et al, 2006) Evidence from Crossmaker (1991) and Carmody (1990), also suggests that 50-90% of people with a disability are sexually assaulted in their lifetime. It is only through a program designed to meet the specific needs of females that these vulnerabilities can be effectively addressed and individuals empowered to recognise and deal with potentially abusive situations.

Initially 'social skills' services for preadolescent girls were time limited in that only one 'school' year of support was available for each client. What was apparent however is that the girls may benefit from a longer term opportunity to be supported to develop friendship skills and indeed long term friendships. Reports from the girls themselves show that many of them fail to form long term relationships with same or similar age peers at school. When discussing friendships Hartup (1992), states that the single best childhood predictor of adult adaptation is not school grades, and not classroom behaviour, but rather, the adequacy with which the child gets along with other children. If the school environment is not conducive to friendship for a child with Autism Spectrum Disorder then it is important that opportunities to 'get along with other children' be provided elsewhere.

Asher, Parker and Walker (1996), state that successful and stimulating shared experiences contribute to a sense of shared history, joint fate, and a perception of investment in the relationship making shared experiences the crucible for friendship formation. It is only over a longer period of time that individuals can build up a history of shared experience, thus time limited services do not provide realistic opportunities for friendships to develop. In addition, although friendships can mature in the settings in which they bud, they are assisted by invitations and opportunities for interaction outside the usual or original setting and an amount of time must pass before individuals feel comfortable making contact with each other outside of a core group (Asher, Parker and Walker 1996).

The case may be argued that schools should provide environments that are able to support the formation of friendships between all of their students or that other longer term activities such as Scouts, Guides or sporting clubs would provide opportunities for these clients. The reality however is that this is not currently the case. Whilst efforts to educate the wider

community about the effects of Autism Spectrum Disorders are ongoing, the capacity for the community to accommodate individuals with ASD's is limited. Currently ASD specific services seem to be the most effective way to support preadolescent girls to form long term friendships.

The issue of abuse is also one that is never far from the minds of people who work with people with autism and the people concerned with their protection such as family members, school personnel and community workers. Given the statistical evidence of abuse of people with disabilities, it could indeed be remiss of professionals not to consider explicitly teaching protective behaviours and to provide ongoing support for the development of healthy self concepts and appropriate communication strategies for conveying personal information.

### The Programs

What evolved from the need for ongoing support is a series of programs including a structured skill development program and a friendship club for graduates of the skill development program.

The structured skill development program is designed to assist girls with Autism Spectrum Disorder to develop age appropriate social, friendship and life skills. Staff members are qualified Developmental Educators who use a variety of techniques including direct instruction, visual strategies, incidental teaching and the promotion of self management to ensure that participants have multimodal access to a curriculum designed to facilitate this development. Sessions are conducted weekly over an hour and a half period and are open to girls aged between eight and twelve years of age.

The Friendship club provides girls with weekly activities and projects encompassing physical activity, art and craft, cooking and audio visual skills. The program was devised and is delivered by staff with additional expertise in these areas. The aim of the Friendship Club is to support the girls to engage in activities and to engage with each other. Each client is supported to develop and maintain friendship skills learned in previous interventions. Each client is encouraged to further develop social networks with peers outside of the Autism SA setting. The generalisation of skills to school settings is considered and regular contact with the School Services Team is maintained.

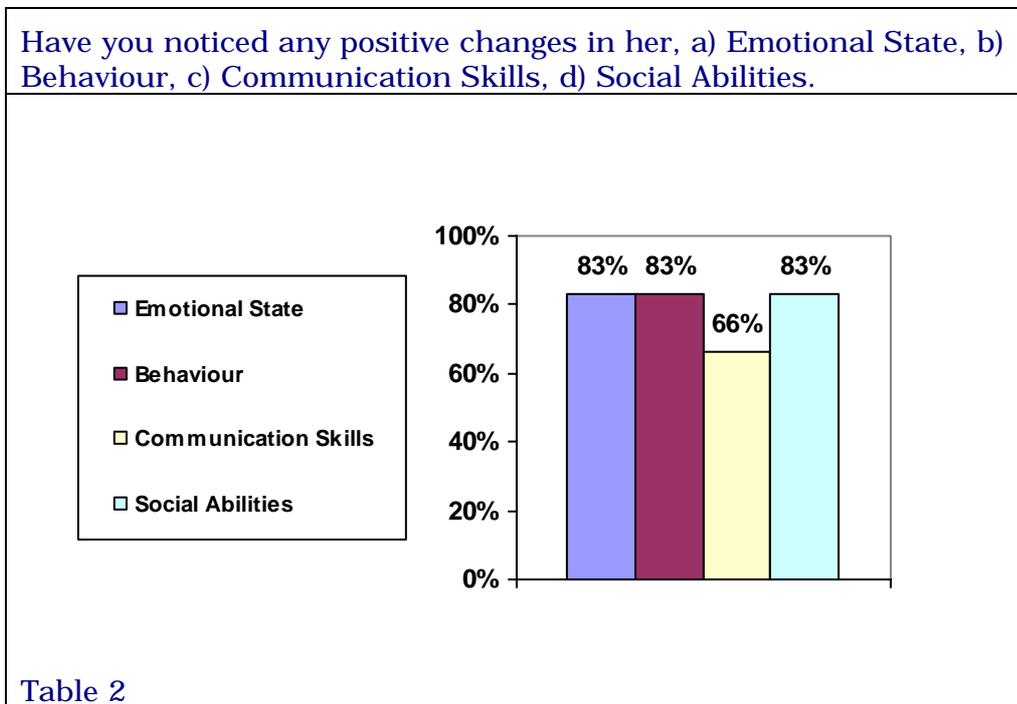
The best practice guidelines presented in a review of best practices in the treatment of social deficits in ASD, Doepke et al (2004) were considered and where possible integrated into the models of service delivery. The organisation is committed to pursuing best practice standards through its quality assured service delivery. The organisation's Policies and Procedures have been adhered to at all times during the development and delivery of this service.

Both programs utilise a range of tools and activities from a range of generic and ASD specific sources. (Table 1)

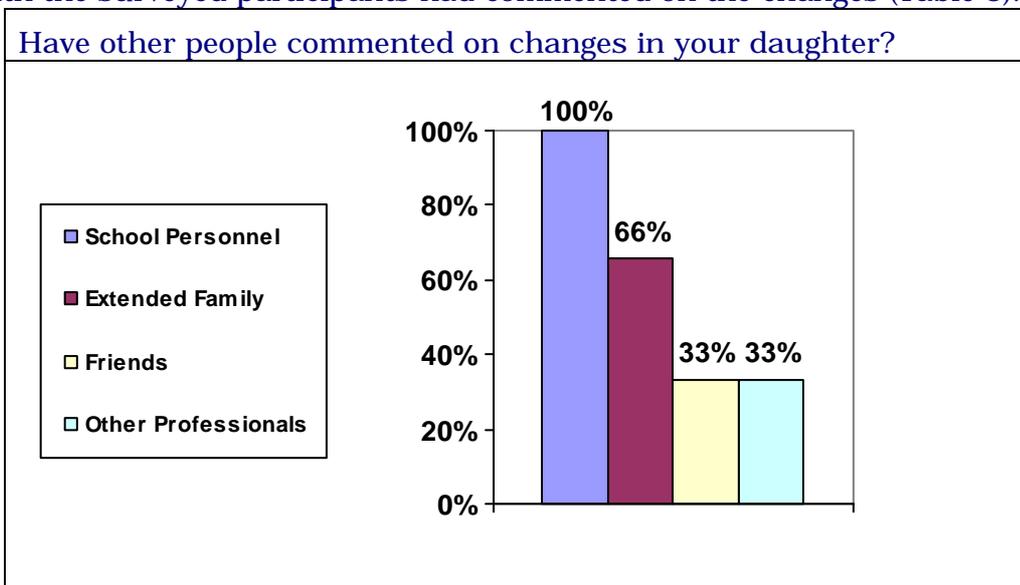
Art and Craft Activities	Activities designed to teach a range of skills and produce tangible outcomes for clients and a sense of belonging through shared activities. Activities include a group wall hanging, a group photo album, sewing and beading projects. Within these activities staff will maximise opportunities for cooperation and social learning. <i>Best Practice #6: Directly Teach Social and Relationship Skills Best Practice #8: Promote Generalisation and Flexible Use of Social Skills and Behaviours</i>
Buddy Time	Buddy Time is one on one time with another girl facilitated by staff. A series of questions are written on a white board to help prompt conversation between the girls. The girls then introduce their buddy to the rest of the group and share things learnt during their conversation. This is very useful in the initial stages of group formation as it provides structure and focus. <i>Best Practice #5: Provide Environmental Modifications and Supports. Best Practice #6: Directly Teach Social and Relationship Skills. Best Practice #8: Promote Generalisation and Flexible Use of Social Skills and Behaviour.</i>
Drama Activities	Activities designed to teach and build social skills taken from a range of sources. Role Play is used to explore difficult situations and role rehearsal is used to explicitly teach protective behaviours. <i>Best Practice #6: Directly Teach Social and Relationship Skills</i>
Free Play	Staff members support participants to choose activities and play mates and help resolve any interpersonal difficulties that may arise. This aims to give participants the opportunity to practice skills in a naturalistic setting, to allow them to choose the nature of their interaction with others and choose from activities available. If difficulties arise during the interactions staff can assist to resolve these and help by modelling appropriate behavioural alternatives. <i>Best Practice #8: Promote Generalisation and Flexible Use of Social Skills and Behaviours</i>
Group Discussion Incorporating Circle Time	Group discussion time is used to facilitate important communication skills such as turn taking, listening, limiting topics, broadening repertoires, entering and terminating. In the tradition of Circle Time concepts developed in the UK, cue cards are used to introduce topics and stimulate discussion. <i>Best Practice #5: Provide Environmental Modifications and Supports. Best Practice #6: Directly Teach Social and Relationship Skills</i>
Group Norms	Group Norms or 'rules' are established with participants and displayed in the meeting room. These norms can be used as a reference by staff and participants throughout the sessions. <i>Best Practice #5: Provide Environmental Modifications and Supports.</i>
Networking Activities	Clients are asked to explore their social networks through 'Circles' activities and discussing the dynamics and mechanics of friendship. Strategies for extending social networks will be explored with clients, their parents and school program staff. <i>Best Practice #6: Directly Teach Social and Relationship Skills Best Practice #8: Promote Generalisation and Flexible Use of Social Skills and Behaviours. Best Practice #7: Involve the Child's Social Partners.</i>
Observation	Each staff member is involved in the ongoing observation of clients, recording anything for discussion at staff planning sessions. This will give staff and parents an overview of the functional skills of each participant and pin point strengths and weaknesses and to provide a baseline to measure changes against. <i>Best Practice #4: Individualise Social Intervention Goals and strategies.</i>
Parent Involvement	Introductory letter to parents sent by group team – who they are, experience, aims for the group, with session outlines, important information, suggestions for promoting new skills. Parents are encouraged to use the facilities to meet whilst their daughter is attending the group. This provides parents with access to peer support and also provides a forum for generating new ideas and innovative ways to support girls with Autism Spectrum Disorder. Term reports for each participant are provided to parents. <i>Best Practice #3: Create a context for effective treatment. Best Practice #7: Involve the Child's Social Partners.</i>
Photographs	Individual photographs taken for a 'who is here' board decorated by the participants. This aims to aid participants and staff with name recall. <i>Best Practice #5: Provide Environmental Modifications and Supports.</i>
Physical Activities	Staff have expertise in delivering a range of physical activities including team games, gymnastics, coordination activities, sensory integration activities, body awareness and protective behaviour strategies. Opportunities for direct instruction and incidental teaching of social skills exist within all of these activities and staff will ensure that clients are exposed to these opportunities. <i>Best Practice #6: Directly Teach Social and Relationship Skills Best Practice #8: Promote Generalisation and Flexible Use of Social Skills and Behaviours.</i>
Schedule	Written on the white board each session and prepared as a picture strip for clients who need extra visual supports. This will prepare clients for the session and reduce anxiety. <i>Best Practice #5: Provide Environmental Modifications and Supports.</i>
Video modelling	Video Modelling/Self Modelling (VSM) is used as a tool to promote self awareness and social success. VSM and Video Journals will be incorporated to provide a tool for reflection and learning. Clients will have the opportunity to record up to 6 minutes of footage per week either of a personal nature or of successful interactions with friends and to review it at home regularly. <i>Best Practice #5: Provide Environmental Modifications and Supports. Best Practice #6: Directly Teach Social and Relationship Skills Best Practice #8: Promote Generalisation and Flexible Use of Social Skills and Behaviours</i>
Visual Supports	Visual supports will be used to enable clients to participate in the program more effectively. These may take the form of picture strips, individual cue cards and written schedules depending on the needs of the individual. <i>Best Practice #5: Provide Environmental Modifications and Supports. Best Practice #4: Individualise Social Intervention Goals and strategies.</i>

Evaluation

Results from a qualitative analysis, using a tool adapted from Bottroff and Zeitz (2004), show that families and people associated with the clients feel that the program is of benefit to them across a number of domains. Parents and guardians have noticed positive changes in the areas of emotional state, behaviour, communication skills, and social abilities. (Table 2)



Results also show that one hundred percent of parents report that school personnel involved with the surveyed participants had commented on the changes (Table 3).



Parents report that the programs have met their expectations in the following ways:

Friendships at school seem to have improved for the better.

She has started to grasp that she has Asperger syndrome and freely tells people about her diagnosis, how she thinks, feels, and is not embarrassed or inhibited.

She has blossomed and made lots of friends.

The group has been a stabilising influence on my daughter and a place where she finally fits in, for me it has provided support and information and with the other parents - a sounding board.

The program has allowed her to discuss issues with her peers.

She has learnt compromise, perspective, and adaptation to new situations. She has gained confidence in speaking in a group and being involved in the group; she has learnt tolerance and assertiveness and has a sense of belonging.

## Discussion

Over the past three years a series of programs have been developed with consideration for the unique needs of girls with Autism Spectrum disorder. Many of the tools used are generic and available to all educators. As has been demonstrated tools have been examined for their fit with the chosen best practice framework. What has been important in the delivery of the programs is the selection of staff for a combination of autism specific knowledge and particular expertise in complimentary areas such as the arts, audio visual technology, gymnastics, sexuality and protective behaviours.

One of the most effective tools employed was Video Self Modelling as described by Buggey (2005), whereby participants could tape successful social interactions experienced in the group setting and experience them again through playback of the video in their choice of setting. Video footage also proved to be a powerful tool for moderating undesirable behaviour. Participants were able to view footage of themselves in unsuccessful situations and work with the group to achieve a more successful outcome. During one such instance an 11 year old with Asperger disorder viewed footage of herself actively excluding another participant. When she realised the impact her behaviour had had on not only the girl that was excluded but the function of the whole group she sought to make a correction by actively including the participant in future activities.

Results of the evaluation show that families and individuals are experiencing positive changes in a range of areas including emotional state, behaviour, communication and social abilities. The generalisation of skills seems to have been supported with one hundred percent of parents reporting that school personnel have commented on changes in participants. Importantly it is apparent through the results of the evaluation and direct observation that friendships have developed and continue to be supported. Many longer term participants now successfully attend community based groups and activities such as Scouts, Cirkids (circus skills), St John Ambulance Cadets, Riding for the Disabled, choir and music ensembles.

Through specific instruction the participants have also been exposed to knowledge and skills relating to protective behaviours and have had the opportunity to rehearse responses to dangerous situations and identify potential risks. The importance of this was brought home when during the course of the delivery of the program the author had to make several notifications to authorities when participants disclosed instances of abuse.

One of the key features of these programs as acknowledged during the evaluation is the fact that the person developing and delivering the programs has an autism spectrum disorder, Asperger disorder. This provides a unique level of insight into the experiences of the participants and coupled with formal education and training provides a platform for the development of an effective series of programs.

Consideration has been given to the future of these programs and further exploration of their effectiveness. Standardised testing is now being undertaken in order to support the qualitative information gathered thus far.

## Conclusion

It is important to recognise that girls with Autism Spectrum Disorder present with a unique behavioural phenotype. Given this and the particular vulnerability experienced by women and people with disabilities in society it seemed imperative to consider an approach to the development of programs that meets the needs of this unique population. When developing these programs tools and activities have been chosen and examined for best fit with an identified best practice framework. Qualitative evaluation of the programs shows promising results that warrant further testing in the form of standardised tests. One component that seems to be effective but could prove hard to measure is the facilitator's direct experience of ASD and the impact this has on the success of the programs.

## References

[Attwood, T. \(1999\). \*\*The pattern of abilities and development of girls with Asperger's Syndrome\*\* \[www.tonyattwood.com\]\(http://www.tonyattwood.com\)](#)

[Asher, S. R., Parker, J. G., & Walker, D. \(1996\). Distinguishing friendship from acceptance: Implications for intervention and assessment. In W. M. Bukowski, A. F. Newcomb, & W. W. Hartup \(Eds.\), \*The company they keep: Friendships in childhood and adolescence\* \(pp. 366-405\). Cambridge University Press](#)

[Bottroff, V., & Zeitz, J. \(2004\). Parent questionnaire. A model of support and intervention for individuals with Asperger syndrome and challenging behaviour and their families: Final report. Flinders University](#)

[Carmody, M \(1990\) Sexual Abuse of People with and Intellectual Disability. NSW Women's Coordination Unit](#)

[Crossmaker, M \(1991\) Behind Locked Doors- Institutional Sexual Abuse. \*Sexuality and Disability\* \(3\) 210-219](#)

[Doepke, K., Kunce, L., Moody, V. \(2005\) Best practices in treatment: Social Deficits. \*The Autism Project: Illinois Autism Resource.\*](#)

[Ehlers, S and Gillberg, C. \(1993\). The epidemiology of Asperger's syndrome: A total population study. \*Journal of Child Psychology and Psychiatry\*, 34\(8\), 1327-1350.](#)

[Gassner, D., Williams, S.K., Sibley, K. A., Rankowski, B. A., Paradiz, V., and Grandin, T. \(2006\) Women with autism differences speak. \*ASA's 37th National Conference on Autism Spectrum Disorders\*](#)

[Hartup, W. W. \(1992\). Having friends, making friends, and keeping friends: relationships as educational contexts. \*ERIC Clearinghouse on Elementary and Early Childhood Education. Urbana IL.\*](#)

[Kopp, S. and Gillberg, C. \(1992\) Girls with Social deficits and learning problems: autism, atypical Asperger syndrome or a variant of these conditions. \*European Child and Adolescent Psychiatry\*, 1\(2\), 89-99](#)

## **Industrial Chemicals May Be a Cause of Autism**

It's not very surprising. Parents and doctors have been saying it for years. But this week, Harvard researchers published an article in the British journal *The Lancet* stating that industrial chemicals could, indeed, be contributing to huge increases in developmental disorders. Here's a citation from [the Harvard press release](#):

Fetal and early childhood exposures to industrial chemicals in the environment can damage the developing brain and can lead to neurodevelopmental disorders (NDDs)—autism, attention deficit disorder (ADHD), and mental retardation. Still, there has been insufficient research done to identify the individual chemicals that can cause injury to the developing brains of children.

In a new review study, published online in *The Lancet* on November 8, 2006, and in an upcoming print issue of *The Lancet*, researchers from the Harvard School of Public Health and the Mount Sinai School of Medicine systematically examined publicly available data on chemical toxicity in order to identify the industrial chemicals that are the most likely to damage the developing brain.

The researchers found that 202 industrial chemicals have the capacity to damage the human brain, and they conclude that chemical pollution may have harmed the brains of millions of children worldwide. The authors conclude further that the toxic effects of industrial chemicals on children have generally been overlooked.

The press release goes on to cite researchers as recommending stronger laws in support of testing and regulating industrial chemical emissions.

Do you have personal knowledge of industrial chemicals that may be causing autism? Can you recommend ways to take action on this issue? Let us know!

#### References:

"Developmental Neurotoxicity of Industrial Chemicals," The Lancet, November 8, 2006- Vol. 368.

Philippe Grandjean, MD, PhD, Adjunct Professor, Marian Perez, MPH, Project Coordinator, Department of Environmental Health, Harvard School of Public Health, Boston, MA, USA. ["Potentials for exposure to industrial chemicals suspected of causing developmental neurotoxicity."](#)

## Temporary email addresses

For a short time, A4 is changing its email addresses. We hope this will cut down the amount of spam sent to these addresses.

If you email A4 and your email bounces, please try to remember this message.

Until around March 2007, please change the email addresses you use to contact A4 according to the table below:

<i>Email</i>	<i>Change from</i>	<i>Temporary change to</i>
<a href="mailto:edit@a4.org.au"><u>edit@a4.org.au</u></a>	edit	editor
<a href="mailto:membership@a4.org.au"><u>membership@a4.org.au</u></a>	membership	members
<a href="mailto:convenor@a4.org.au"><u>convenor@a4.org.au</u></a>	convenor	cnvnr

## A4 Contacts

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

**Update team:** [edit@a4.org.au](mailto:edit@a4.org.au)

Editing team: Juanita and Vicki

Reporting team: we currently have vacancies in all states

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

### ***Steering Committee***

**A4 Convenor:** Bob Buckley, ACT  
[convenor@a4.org.au](mailto:convenor@a4.org.au)

**Treasurer** (donations): Cathy Ryan, Vic.  
[treasurer@a4.org.au](mailto:treasurer@a4.org.au)

### **Members:**

Cathy Ryan, Karen Mackie, Kelley Harris, Vern Hughes, Lionel Evans, Judy Brewer Fischer, Geraldine Robertson, Wendy Kiefel, Mary Gebert, Katharine Annear, Myrna Dominguez, Vicki McKay