UPDATE
Autism Aspergers Advocacy Australia
September 2006
Issue 5

Parents Story – the last episode

Name withheld by request (29/07/06)

Where were we? For those who came in late...

Our son was diagnosed with AS late the year he entered high school.

Despite assurances etc, the year ended with us taking him out of the school because we believed the school had failed in its duty to care, educate or protect him.

That undersells the situation badly. It was our – and our son’s - *annus horribilis*.

We had magic help in getting him into a new school where AS was recognized and catered for. In fact two teachers in particular helped bring our son back from an abyss.

Trust me; I am not exaggerating the situation we were in.

The fact that one teacher in particular took the time to ring us one night just to tell us our son had had a really good day was enough to bring both my wife and myself to tears.

All was going well and our son was progressing well. We could find no fault with the school. It was performing well as far as we were concerned albeit with the odd bump.

But it was nothing the school, our son or we could not deal with.

Then the phone call: *trust me – I am not making any of this up.*

I won’t use space to detail the sequence of events. Rather, the following is the letter – edited for legal reasons - which followed.

Inside this Issue

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The Principal,

Dear Sir,

It disappoints me deeply that both you and some members of your staff have failed in both your duty of care for my son, and that you have failed to report to me at the earliest possibly opportunity of the dramatic failure in that duty of care.

On Tuesday, February 8, my son with other Year 12 students went on a school-led excursion (to a university).

After the excursion the staff left the university without him and returned to the school.

That this happened is bad enough; that this happened to a child with a disability is appalling; that the teacher apparently leading the excursion was not aware that a student under his care had a disability is inexcusable; that I had to call you for an explanation is unacceptable; that I have had no contact from you – the principal – nearly two weeks after this most dramatic failure by the school of its most basic responsibility towards the students under its care I find intolerable.

To the events:

After a call from an extremely agitated and upset son around 2.20pm on February 8 informing me that he had been left behind at the university, and further calls to the school, I had some contact with a teacher who seemed to be in charge of the excursion (although to this point this has never been confirmed to me) who organised for our son to get home.

The teacher rang me 24 hours later – and a 24-hour delay in a matter of such seriousness is unacceptable by any standards in my opinion - to tell me how well our son had handled the whole situation both at the university and on the trip home (the teacher had returned to the university and taken our son home).

I was able to point out that:

Our son rang me in an extremely agitated and distressed state from the university when he realized he had been left behind and, he had been polite on the way home because my wife and I told him to be.

The teacher claimed – among other things – that our son had been possibly “misdirected” while at the university as to the departure point, and that when everyone (apart from our son) arrived at the departure point early there was pressure from the bus driver to leave as soon as possible.

I asked why had there had not been a proper count of the students, which surely would have picked up that someone was missing, but the answer to that was vague at best.

I told the teacher his comments were not good enough and that the school and teachers involved had failed in the worst possible way in their duty of care towards a child under their supervision.

I pointed out that the fact that the child had a disability made their failure to maintain that duty of care even more deplorable.

At this point the teacher told me he did not know our son had a disability.

As I have pointed out, this takes the failure of the school – and the teacher - to maintain a duty of care towards our son to untold and unacceptable new depths.

I told the teacher that I required an explanation from someone higher than him as to what went wrong, and that the explanation would not want to be just a repetition of the “he was missed at the head count” line.

He told me that the assistant principal (senior school) would ring me late the next day – a time, which I indicated, would be acceptable to me.

> On the morning of February 10 – after I put a call in to your office to determine, among other matters, your own awareness of the situation and some 44 hours after the event – the assistant principal called me and indicated to me that the school was treating the situation very seriously.
>
> She pointed out that the situation should never have occurred.
>
> I was told, among other things, that:
>
> The group – without our son – arrived at the departure point early and that the bus driver demanded the bus leave early because of other commitments.
>
> That instead of ticking off names from a list, as per what I understand to be Education Department standard operating procedure, a simple head count was made when it was time to leave.
>
> That it was discovered that our son was missing 10 minutes after the bus left the university by which time the bus was on (a freeway) and could not turn around.
>
> That the bus driver said the bus had other commitments and could not return for our son.
>
> That human error was to blame.
>
> The assistant principal agreed the situation was unacceptable and that she was extremely sorry.
>
> She agreed with me that central control should have rested with the teachers and not the bus driver.
>
> She further agreed that the teacher’s failure to make himself aware of our son’s disability prior to the excursion was “sloppy”.
>
> I suggested that “sloppy” did not cover it.
>
> She pointed out that the school’s excursion policy would be re-examined.
>
> She explained, and I accepted, that our son received an apology and that staff had taken steps to ensure there was no teasing or harassment following the incident.
>
> I find it baffling – and insulting – that nearly two weeks after the event, I am still waiting for you to return my telephone call of February 9 concerning this most serious matter.
>
> I simply ask for three things:
>
> A written apology from the school,
>
> Written acknowledgement and official confirmation that the staff involved and responsible have been made - formally and officially - aware of their responsibilities towards students under their care, disabled or otherwise,
>
> A written assurance that the school has re-examined its excursion policies and has taken steps to ensure that such an incident cannot happen again.
>
> I look forward to your most urgent response in this matter,
>
> Yours sincerely etc.

It is now August 2006 and I am still waiting. Just how wrong can a “good” school get it?

And if that was a good school – and it was – then what’s going on at the others?

It is now six years since our son was diagnosed with AS and we have been through hell and back, the hard way. Our son is now back at school (another school) completing Year 12 over two years as an adult student. He seems to be doing well.

Writing these pieces still bring me to tears of anger and joy.

What have we learnt? Well, I will try to summarise.

TAKE notes. Uninformed complaints and vague allegations made without names, dates and times are ineffectual.

DON'T get angry – get even.

IF at first you don't succeed, don't be afraid to take your complaint/concerns to a higher level.

SHIT happens.

BE prepared for anything.

DON'T ever – when things go wrong – accept the first explanation trotted out.

And I have taken these last three pieces of advice from the collected quotations of Sir Winston Churchill which I found useful during the trials and tribulations.

IF you are going through hell, keep going.

COURAGE is what it takes to stand up and speak; courage is also what it takes to sit down and listen.

IF you have an important point to make, don't try to be subtle or clever. Use a pile driver. Hit the point once. Then come back and hit it again. Then hit it a third time-a tremendous whack.

And a post script if I may:

Not long ago at a social event I bumped into the assistant principal who had managed almost single handedly to destroy my son's life at his first high school.

He asked me what our son was doing now.

I simply said to him that we were still angry at the way he had dealt with our son, but that our anger – over time – would wane.

He, on the other hand, I said, was a bad teacher – and that would never change.

I hope my anger subsides soon.

Convenor's message

Dear A4 member,

I am sorry my message is rather rushed this time.

First I want to say how much I appreciate the huge effort put in by Wendy and Peter Keifel in preparing A4's Submission to the Senate Community Affairs Committee's Inquiry into Funding and Operation of the Commonwealth State/Territory Disability Agreement (CSTDA). From what I can see, there were further contributions form Mary Gebert and Geraldine Robertson. And Helen Curtin put in a massive proof-reading effort at very short notice.

The CSTDA is very important for disability services. It is the political process that effects "specialist disability services", services and support that are for people with a disability and not for the rest of the community. These are services like respite, community access, advocacy, accommodation support for people with a disability, employment support, etc. The CSTDA is about services from both the federal and state governments.

Thanks all those people who put in submissions. The Committee publishes submissions here. The following submissions appear to be associated with A4:

- Autism Aspergers Advocacy Australia, A4 (PDF 627KB)
- Kennedy, Ms Catherine (NSW) (PDF 13KB)
- Name withheld (PDF 61KB)
- Ratten, Mrs M (SA) (PDF 10KB)

- Buckley, Mr Bob (PDF 376KB) (*this is my personal submission, it is not on behalf of A4 or any other organisation*)
- Minchin, Lisa; Mroz, Melissa; Dodgson, Kim; Sont, Arahni; Ratten, Bryan; Bewley, Lyn; Lie, Cindy; Kasner, Jenny; Cooper, Darani; Wright, Fiona (PDF 56KB)

Please take a look at what others have written, and consider saying something yourself to future government inquiries. Actually, it's not too late to send something to this Inquiry. You don't have to send anything complicated … the simpler the message the better.

Other submissions that make significant mention of autism include:

- Gippsland Carers Association Inc (VIC) (PDF 569KB)
- Walsh, Mrs Mary (QLD) (PDF 83KB)
- National Carers Coalition (VIC) (PDF 901KB) Att 1 (PDF 372KB)
- Metro North Disability Support Group (NSW) (PDF 61KB) Att 1 (PDF 54KB) Att 2 (PDF 393KB) Att 3 (PDF 134KB)
- ACROD (ACT) (PDF 196KB)
- Collier, Dr Paul (SA) (PDF 14KB) Att 1 (PDF 2671KB) Att 2 (PDF 590KB)
- Client Guardian Forum Inc (ACT) (PDF 124KB)
- Name withheld (PDF 121KB)
- Carroll, Mr Michael & Paterson, Ms Alli (WA) (PDF 35KB)
- Disability Advocacy and Complaints Service of SA Inc (DACSSA) (SA) (PDF 127KB)
- Shepherd, Ms Di (WA) (PDF 16KB)

I was interested to see Attachment 1 to Dr Paul Collier's submission. Clearly, the UK government takes ASD far more seriously than does the Australian government.

This CSTDA Inquiry is federal politics. Inquiries like this happen at the state level as well. A4 needs people to keep an eye on each state. If you notice anything like this happening in your state, please let us know so we can help and encourage people to speak out on these issues.

I expect most of you saw the SBS Insight program on Autism. If not, you can go to the SBS website and see what is there. Thanks to all those involved: especially to those brave enough to expose their very personal lives and feelings on national television.

Personally I was disappointed that none of the relevant political leaders was involved; nor were any of the national organisations. SBS management never explained to me why that was.

You may have noticed some new questions on disability in the National Census. It will be interesting to see what the information tells us. It will not identify people with autism but it may provide some data to government on disability generally in our community.

The media has given some coverage to cases where the government has denied or cut off services for people with a disability. The Age had a story about a teenager who is blind and has a cleft lip and palate, epilepsy and severe Asperger's syndrome and who has been denied the disability support pension (DSP). According to the story, "He gets only $220.30 a fortnight — rather than the $315 he would receive on the pension, which would help pay for the taxis he uses."

I think it is good that the government wants people with a disability to have jobs. Many of the people with ASD that I know would like to work; they want to work and contribute to the community. But governments and their agencies are not interested in understanding and overcoming the real barriers that prevent many people with ASD from having and maintaining a job.

I anticipate the government will disallow the DSP for hundreds of people with ASD … because government and its agencies do not understand ASD. It is the same old story: their staff cannot see ASD and have not been trained appropriately.

If this is happening to you or to someone you know, and you think it is unjust, then you should say something. If you are not sure what to do, then please let us know.

Some time ago, I wrote as an individual (not on behalf of A4) to each of the states and territories asking a series questions. Most of them responded. For the impatient among you, the questions and the state and territory responses are on my own website (see http://bbuckley.com/ASD/states/index.html) … except Victoria who didn't respond. I would be very interested to hear how you feel about what your state says about its services and support for people with ASD.

In the future, I plan to say much more about what the states say they are doing and the reality people with ASD experience.

Thanks to all the people who sent me stories for Mr Christopher Pyne MP (see the last Update). Soon, I will write to thank you individually for your help and to let you know what is happening. If you haven't got around to it yet, it is not too late to send in a personal story.

A4 wrote to Mal Brough MP, Minister for FaCSIA, seeking a meeting about the exclusion of people with ASD and without intellectual disability from initiatives described in the last federal budget. As yet he has not responded.

There is more I'd like to write about, but it will have to wait until next Update.

Regards
Bob Buckley 18/8/2006

A4's New Steering Committee

A4 has a new Steering Committee. Currently, the members are

Name	*Interest(s)*	*Location*
Bob Buckley	Convenor	ACT
Cathy Ryan	Treasurer	Vic, metro
Karen Mackie	accommodation models/support for adults with ASD	NSW, metro.
Kelley Harris	publications & promotion	Vic, regional
Vern Hughes	education, employment, family governance models	Vic, metro
Lionel Evans	Policy and Advocacy, Asperger's in regional areas	Qld, regional
Judy Brewer Fischer	Carer services (and everything else)	Vic, regional
Geraldine Robertson	Education and any issues concerning adults	Tas, regional
Wendy Kiefel	Health and education	Vic, metro
Mary Gebert	Education, Research & Medical	Vic, metro

Katharine Annear	Girls and Young Women with ASD's, Adults with ASD's, counselling for people on the spectrum, Research, Community Education	SA, metro
Myrna Dominguez	early childhood, promoting inclusion for young children with ASD	NSW, regional
Vicki McKay	A4 Update	Vic, regional

A number of people have left the Steering Committee. I would like to express my enormous appreciation for their help. I am sure they will continue doing great things for our causes.

I would especially like to welcome the newcomers to the A4 Steering Committee. I know they will find the role challenging but I hope they are able to enjoy doing it.

Please, give these people support in what they are doing. Their role is representing the views of all the members. Please let them know what you think on issues so they are able to represent your view.

We would like some more people to be involved. For example, some states are not represented. Do you want people with ASD to have a better life than they currently do? If so, please consider joining the A4 Steering Committee. Do you know someone who should be on the Steering Committee? If so, ask them would they object … and if they don't, then nominate them.

Are you enthusiastic about making life better for people with an ASD? You do not need to know a lot about ASD or about politics. You should be prepared to say what you think about what interests you. There is no need to agree with the rest of the committee … diversity is good!

Please, let me know if you need more information about what is involved in being on the Steering Committee. We can help you learn what we do and how we do it.

Living with Asperger's Syndrome: Harold Stone

On Wednesday 19 July 2006 (during Disability Action Week) Trevor Jackson in his ABC Radio Coastal Conversations segment, spoke with Harold Stone, president of Asperger Services Australia (aka Asperger's Syndrome Support Network (QLD) Inc) and person with Autism. The chat was more a "real conversation" rather than an interview. See transcript and/or audio link at http://www.abc.net.au/goldcoast/stories/s1690914.htm

Rare counting ability induced by temporarily switching off brain region

http://tinyurl.com/hns8z
Friday, June 09, 2006
Snyder, A., Bahramali, H., Hawker, T. & Mitchell, D.J. (2006). Savant-like numerosity skills revealed in normal people by magnetic pulses. Perception, 35, 837-845.

A minority of people with autism have one or more extraordinary intellectual talents, such as the rapid ability to calculate the day of the week for a given date, or to count large numbers of discrete objects almost instantaneously - they're often called 'autistic savants' or 'idiot savants'. Now Allan Snyder and colleagues have shown that by placing a pulsing magnet over a specific area of the brain, these kinds of abilities can, to some extent, be induced in people who aren't autistic.

Twelve healthy participants were given several chances to estimate, from 50 to 150, how many blobs appeared on a computer screen. The blobs appeared for just 1.5 seconds, and the number of blobs changed on each attempt. Remarkably, the performance of ten of the subjects improved drastically after Snyder's team applied 15 minutes of low frequency transcranial magnetic stimulation (TMS) to their left anterior temporal lobe, a brain region that's been implicated in autistic people with rare counting and calculating abilities.

For example, before the TMS, one participant had 20 goes at estimating the number of blobs onscreen, and each time she was more than 5 away from the true figure. Yet immediately after receiving the TMS, she made 6 out of 20 guesses that were within 5 blobs of the true figure. Before TMS, another participant scored 3 estimates out of 20 that were within 5 of the true figure, compared with 10 out of 20 immediately after the TMS.

The enhanced ability was gone within an hour, and moreover, no such improvements followed application of a sham version of the TMS that made all the same noises, but was applied only weakly over a different brain region. In fact, the participants' performance deteriorated slightly in this condition.

The researchers think that by temporarily inhibiting activity in the left anterior temporal cortex, the TMS allowed the brain's number estimator to act on raw sensory data, without it having already been automatically grouped together into patterns or shapes. In other words, they believe it caused the 'normal' brain to function more like an autistic 'savant' brain. “We argue that it removes our unconscious tendency to group discrete elements into meaningful patterns, like grouping stars into constellations, which would normally interfere with accurate estimation”, the researchers said. “By inhibiting networks involved in concepts, we may facilitate conscious access to literal details, leading to savant-like skills”.

***Update**: Not all people who show the rare counting and calculating abilities discussed in this report are autistic. However, according to the source paper, most are.*

New research on prevalence of autism highlights need for services

Research by Gillian Baird and colleagues, published in the Lancet, conducted on prevalence of disorders on the autistic spectrum, concludes that the prevalence of the disability is substantially higher than previously recognised, stating that children with an autistic spectrum disorder (ASD) constitute 1% of the child population.

These findings show that the National Autistic Society (NAS)[1] prevalence estimate of 1 in 110 people with ASD is matched by current research, and, similarly, concur with recent findings from the Office of National Statistics 2005 which stated 0.9% of the child population of Great Britain has a form of autism. It is unclear whether the increase is due to better understanding of the disability, broadening diagnostic criteria or increased incidence. These uncertainties will emphasis the pressing need for funding for further research into autism.

Mike Collins, NAS Head of Education, says:

> "This research underlines the importance of appropriate services for individuals with autism. Current provision for those with the disability is deeply inadequate given the scale of the need. Government and local authorities must ensure that education, health and social services are adequately funded and all staff appropriately trained in order to meet the needs of those living with the disability and their families. Autism is a lifelong disability and when an individual's needs are not met the long term consequences both financially and for the individual's well being are profound."

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[1] National Autistic Society (NAS) is the UK's leading charity for people with autism

A Can-Do Approach to Autistic Children and Athletics

New York Times, United States, 2 Aug 2006
http://www.nytimes.com/2006/08/03/fashion/03Fitness.html

The members of the swim team at Bloomington High School South in central Indiana cheer wildly every time Nathan Buffie races. In his two years on the team, Nathan has never won first place at a meet. Often, he finishes far behind.

But it is the fact that Nathan even goes into the water and manages to compete at all that his teammates find so remarkable. Nathan, a trim 16-year-old with a boyish smile, has autism, the devastating developmental disorder that makes his participation in any sport or social activity a struggle.

“He is probably the worst swimmer on the team, but he keeps getting better and he wants to win,” said his mother, Penny Githens. “He tells his teammates this, and they just get so excited for him.”

For years, children with autism were left on the sidelines, a consequence of a widespread belief that they were incapable of participation in athletics. But while it is true that autistic children can be difficult to motivate and resistant to exercise, they are now being pushed to take part in physical education programs, encouraged by experts who say that certain sports can ease repetitive behaviors like pacing and head-banging as well as provide a social outlet.

Autistic children, even those who are considered low functioning, can excel at activities like swimming, martial arts, running and surfing - sports that don’t entail having to read social cues or figure out when to pass the ball.

“A lot of autistic children are never going to play on a team, but they can do really well in individual sports,” said Donna Asher, the camp director at the North East Westchester Special Recreation Program in Hawthorne, N.Y. “It’s not their physical skills that keep them from participating, it’s their social skills - not being able to interact with others or having a breakdown on the field in the middle of a game.”

Athletic programs for autistic children, often called adapted sports programs, are designed to sidestep social and behavioral problems.

Many autistic children — up to half, according to some studies - are prescribed antipsychotics and other drugs that can produce fatigue and swift weight gain. Studies show that about 17 percent of autistic children are overweight and another 35 percent are at risk, figures that mirror the rate among American children in general.

Experts hope that teaching autistic children how to be active will stave off problems later in life. “What we’re trying to do is to make sure that they won’t be at high risk for obesity and coronary artery disease,” said Dawn D. Sandt, an assistant professor of adapted physical education at the University of New Mexico who has studied the activity levels and the body mass of autistic children.

Still, for parents of autistic children, locating an adapted sports program can be a low priority. More often than not, they are consumed with struggles to find speech therapists, behavioral intervention services, special education classes and a health insurance policy that will pay for it all.

“Parents of autistic kids have a lot of battles to fight,” said Georgia Frey, an associate professor of kinesiology at Indiana University in Bloomington, who founded an adapted physical education program in 2001. “So when it comes to getting their kids involved in recreation and physical activity, it can seem too exhausting. But I do think that parents see the value in these programs, because the demand for them is very high.”

Researchers say the value of sports for autistic children is well documented but often overlooked. Studies dating back to the 1980’s have found that brisk physical activity increases attention span and reduces repetitive behaviors.

But the catch is that the exercise must be moderate to vigorous. One early study of autistic children found that 15 minutes of jogging “was always followed by reductions in stereotyped behaviors” such as hand-flapping and rocking. But 15 minutes of playing alone with a ball, considered mild exercise, had “little or no influence” on behaviors.

John O’Connor, an associate professor of adapted physical education at Montana State University-Northern, explained why. Running and swimming involve rhythmic movements that are similar to stereotypical behaviors, and may distract people with autism the same way flapping their hands or walking on their toes does.

“People with autism experience levels of sensory perception that most of us wouldn’t know or understand,” Dr. O’Connor said. “It overloads them, so they engage in behaviors that distract them. Exercise gives them the same benefits but it doesn’t have the negative social connotations.”

As many as 1 out of every 166 children born today has autism, according to the federal Centers for Disease Control. No organization tracks the number of participants in adapted physical education programs or how many such programs exist.

Because the severity of the condition varies, the challenges instructors face are never the same. Some children are withdrawn, others will engage. Some speak fluently, others are mute.

The Aqua Pros Swim School in San Diego has a program called Pool PALS (Persons with Autism Learning to Swim). There, teachers incorporate pictures and marker boards into their lessons to demonstrate proper stroke technique to children who have trouble communicating. The school also has a mechanical platform that can be lowered into a pool inch by inch to gently introduce reluctant children to water sports.

Tammy Anderson, the private swim instructor who runs the program, started it about five years ago after she met a woman who doubted that her nonverbal, tantrum-prone 7-year-old daughter would ever swim a lap. “I saw that as a challenge,” Ms. Anderson said. Every lesson had to be broken down into small steps that were demonstrated with flash cards and other visual cues. After a month and a half, she said, the girl could swim across the pool “with a pretty decent stroke.”

“Her mom came back to me in tears and said it was the first thing that anyone has ever been able to teach her daughter,” Ms. Anderson said.

Pool PALS now has more than 100 students, up from 30 when it started. It spawned a surf program with 80 participants, up from 14 when it began in 2001. Both programs have waiting lists.

Because autistic children often do better with routines, most programs are highly structured. At the Westchester camp, which serves children with developmental disabilities and emphasizes fitness, campers are provided with a detailed daily schedule. Instructors keep the campers engaged and ready to participate. “Left to their own devices, these kids will retreat into their own little worlds,” said Ms. Asher, the camp director.

The hope of the adapted programs is that participants will pursue a sport for life. Then there are the best-case scenarios like Nathan Buffie in Indiana, who started in an adapted swim program at a Y.M.C.A., graduated to a community program and eventually proved capable of swimming for his high school team. He also participates in an adapted martial arts program at a Y.M.C.A.

His mother, Ms. Githens, said that Nathan stumbles sometimes. He doesn’t always line up when he should, and he has problems controlling his voice. But the swim team has embraced him nonetheless.

“When he is out in the water,” she said, “his teammates yell and scream for him in a way that they don’t for anyone else.”

Letters / Emails

Please send letters to edit@a4.org.au. Letters sent to the editor may be published unless they are clearly marked “not for publication”. Normally, they will appear with your full name and state unless you mark them clearly “anonymous” or “first name only”.

Front page from the Daily Mail in England

Ken and Tammy Holder (28/7/06)

We have just returned from a holiday in the UK. This was a once in a lifetime trip where we took our two daughters and our 6 year old autistic son on a month long trip to England to spend some time with close family and friends. We have many tales to tell and met many challenges! But these are stories for another day (which we are happy to share).

Whilst we were there, we noticed that one of the major newspapers, The Daily Mail, on 14 July 2006, ran as its front page story: **Autism at a record high**. Coming from Australia where it appears difficult to raise even a murmur in the press about ASD it was amazing to see this as the “single” front page article on a leading daily newspaper. I can't say whether the content of the article is remarkable, but certainly the exposure on the front page was.

If anyone is interested in the story it can be found on the web at: http://www.dailymail.co.uk/pages/live/articles/news/news.html?in_article_id=395567&in_page_id=1770&ct=5

Story about my son Jordan, aged 9

Rachel Semmens – VIC (20/7/06)

My son Jordan, born May 1997, was diagnosed with Asperger Syndrome 12 months ago, aged 8. Unfortunately for Jordan, we had a late diagnosis and if detected earlier things may have worked out differently for us.

At a young age of 3, we suspected Jordan was a little different to most kids his age. Jordan seemed more sensitive emotionally than other kids we knew, however, no one at pre-school ever said anything to us to make us feel an assessment needed to be done.

Jordan started school as per usual in 2003; he was 5½ years of age and ready. Our first year of prep was an experience to have had, right from the start we had bullying issues, there was not a day that went by that Jordan did not struggle through the day. A lot of the bullying was verbal and therefore not handled very well by the school itself.

In second term things got worse, we had school refusal on our hands. Jordan would hide in cupboards or out in the playground and we were called in for meetings with the teacher and principal on a weekly basis. Jordan was labelled as a bad behaved child suffering from Oppositional Defiant Disorder (diagnosis made by the principal at the school). Jordan was sent from classroom to classroom, always in trouble and finger pointed at home, judging that there were issues in his personal life.

Jordan at home was and still is beautiful; he has a kind and gentle manner. It’s when life is frustrating that that situation is turned around.

In third term Jordan started receiving physical bulling at the school, he was urinated on; spat at; dog pooh placed in his pocket and a fractured foot in three different places (due to children jumping on him from the playground). We were horrified and at the end of September that year we pulled Jordan out of that school. At the start of the final term we enrolled Jordan into a small local government school close to home, by the time first term of 2004 (grade 1) came along things were looking bad again. Jordan spent a lot of time in the time out corner and was sent to other class rooms as his teacher had no idea how to make Jordan settled, by the time Jordan was 7 years of age he was drawing pictures of himself dead and other pictures of his class mates killed. He was talking death all the time. At this point in time I had a daughter who was 1 and was struggling to work outside of the home due to Jordan’s emotional state.

We booked Jordan in to see a physiologist and we were told that he was depressed, but that was all. What were we to do?

School became a nightmare, not just for Jordan but for the whole entire family.

Even I hated it… therefore found it very difficult to encourage Jordan to go. He was constantly put down about his behavior and about his obsessions. Jordan now had no self-esteem or confidence; and on a daily basis would threaten suicide.

In September 2004 Jordan was strangled in the play ground, we went home and never returned. The principal never called to see what happened or to find out if we were ok. Six weeks after our last day I wrote a letter regarding our disappointment and the concern that we were on a waiting list to see the school councilor for 15 weeks with no visit.

In 2005 we reluctantly enrolled Jordan into his 3rd school for grade 2.

This time we choose an alternative private school as mainstream had let us down.

Jordan still struggled and after trying to kill himself one day out at a shopping centre, we sought a third opinion from a GP who referred us to a Paediatrician, she was fantastic and instantly spoke to us about Asperger Syndrome, we had never heard of it before. She referred us to see a Physiologist and in the meantime we researched the disorder and studied it back to front. I felt like some one wrote the information from Jordan's history, I was amazed at the similar traits and eager to find out Jordan's results.

In August of 2005 (Jordan was 8 and 3 months of age) we were given a professional diagnosis of Asperger Syndrome. Jordan started medication ASAP (anti-anxiety medication, which he is still on) unfortunately the alternative school we were at do not believe in disorders and do not accept children who are medicated and we were asked to leave immediately. They too were nasty in their treatment of Jordan and I could understand why my son hated himself so much.

I decided at this point in time to keep Jordan at home and give us all a well deserved break from school and society. We became or felt isolated; isolated from what we so call the real world - what is the real world- what is normal?

I was pleased to hear that we were eligible for the carers allowance and given a health care card for Jordan, yet my disappointment continues to linger when I recently found out that his medication is no longer covered - is the government trying to torture us?

In February 2006 Jordan started at a Currajong School, a special school for children diagnosed with ASD or who have emotional behaviour problems.

WOW what a school - it's wonderful, it's kind of like having a world away from the world, a world that understands Jordan and one that understands us.

The sad thing is that it is privately run and is no funding given to parents for children who attend, therefore financially putting a strain on the family. I am driving 4 and ½ hours a day back and forth to school. I am also juggling a 3 year old and have had to increase working hours to cover the cost of fuel, medication and school. We have also tried to seek help at home to try and keep the family together and have a teacher from Autism Action[2] come to the home to help us privately, meanwhile not getting any funding for these things. When money is tight it puts such a big strain on the marriage.

My goal for Jordan is happiness, I want him to love life and get through life with a meaning of some sort, and I want society to accept him and others with difficulties. I want Jordan to have

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[2] *Autism Action is someone who specialises in special needs and helps us implement visual cards and good parenting skills to cope at home with a child like Jordan. They also help us blend both the children together as it can get difficult when trying to get both kids to play together.*

a better self esteem and to have confidence in himself. Problem is, where do we go from here?[3] The dream seems fine for a moment but what happens next. What happens to us as a family? Can we survive this financial burden? Trying to be normal (what ever that is), pay off a mortgage, and cover the cost of fuel and school. What do I do when my daughter needs school, do I place her close to Jordan's or home?

Where is my emotional support?

The devastating thing is that it's not just me. There are others in the same situation and I guess lucky for us that we got in the school, as it can only cater for 66 children. What happens to the rest? Why is no one out there supporting these wonderful, bright children in our country? Does any one care?

So many questions so little answers...

Glad to have been heard finally. Seriously frustrated.

Autism Seminar with Diane Yapko on 21/9/06 at Woollahra, Sydney NSW

Arahni Sont – NSW [29/8/06]

Editor's Note: *Arahni Sont is a mother of a 15 year old autistic boy, she has organised this talk on her own initiative: She contacted Diane after seeing a flyer about her. Diane has agreed to do this seminar while on holiday in Australia.*

The seminar will be held from 12.30 to 4.00 pm on 21 September 2006 at Holdsworth Street Community Centre, 64 Holdsworth Street, Woollahra, Sydney, NSW (the eastern suburbs). To secure your place, **full payment** of $140 must be received by 10 September by sending your cheque payable to Arahni Sont, 42 View St, Woollahra NSW 2025.

Please include full contact details including phone, email and address. **Participation is limited to 22 people**. Please note that lunch will not be served, but there will be a 15 minute coffee break.

Diane Yapko, M.A, Speech-Language Pathologist www.dianeyapko.com

Most parents, carers and therapists who work with children on the Autistic Spectrum are continually looking for strategies and techniques to improve the lives of the children with whom they live and work. In this half-day workshop, we will do exactly that by exploring a naturalistic model of intervention that Diane Yapko has integrated into her private practice and written about called ***The Utilization Approach***.

Originally developed by the pioneering psychiatrist, Milton H. Erickson, M.D., known for his creative and strategic interventions, *The Utilization Approach* emphasizes the importance of joining the client's frame of reference, and utilizing his or her history, values, interests, behaviour and expectations in the intervention. Diane has integrated the approaches she has used as a speech pathologist for 25 years, with the common sense principles of *The Utilization Approach* and has adapted them to the special needs of children with ASD and other social-language impairments.

In this half-day workshop, Diane shares practical strategies that she uses with **children of all ages.** Whether working with a toddler that is two or three years-old, an elementary school aged child or an adolescent, Diane emphasizes the positive aspects of what the child brings to the social context and strategically employs techniques and homework assignments that can

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[3] *In regards to high schools: there are private schools that run a special program for kids with ASD but no state school. They apply for an aid which we could get 3hours a day: no way is that enough to help. It's just that having a special school for primary is great but what happens next, we go from a school who understands our needs and has 11 kids per class room and 66 in total, to a high school of 25-30 in each class and any where from 700-1200 students - that's scary.*

help to facilitate a positive change for the child. The emphasis of this workshop is on higher-functioning children, but the principles are the same for those individuals who are struggling with more severe impairments.

Diane will share different strategies and teach participants strategic thinking so they are equipped to handle the variety of challenges we are presented with daily. Having a variety of therapeutic tools in the clinical "tool chest" makes good sense and this workshop is designed to give participants more tools to use in working with children on the autistic spectrum.
For more information please contact Arahni Sont asont@bigpond.net.au.

Participation in a book about what it's like to get a diagnosis as an adult

Michael John Carley, New York [28/8/06]
GRASP (The Global and Regional Asperger Syndrome Partnership, Inc. www.grasp.org)

I am the author of an untitled work about what it's like to be diagnosed as an adult or young adult with an autism spectrum condition such as Asperger Syndrome. The book is to be published by Perigee Books, a division of Penguin Group (USA) Inc.

I am asking for written testimonials from any of you (that will definitely be edited) and possibly used in the book.

For more information please contact Michael on mjcarley@grasp.org

Monash University Research: Genetic analysis of Autism in multi-generational families

Conducted by:
Monash University, Department of Developmental Psychiatry and Psychology
http://www.monash.edu.au

Background: Autism is a complex neurodevelopmental disorder characterised by significant disturbances in social, communicative and behavioural abilities. Although certain regions in the human genome have been linked to autism, no genes have yet been identified. This is due in part because autism is not a specific disease, but a collection of disorders, probably determined by a number of different genetic factors. The study of unrelated families who have a child with autism has limited power for gene discovery, unless the same gene was responsible for autism. Unfortunately, this does not appear to be the case as recent studies using large numbers of unrelated families have not been able to identify autism genes. An alternative approach is to recruit multigenerational families with a number of affected members who have autism. This type of collection should provide greater statistical power for gene identification because it is more likely that a similar pattern of genes contribute to the onset of autism in these distinct families.

Aims: The major goal of this project is to identify and characterise autism susceptibility genes by studying multigenerational families who have a number of members with autism. We need to study as many family members as possible in the wider family because genetic information from unaffected individuals is as important as that obtained from those with autism in helping to define possible gene causes.

In this regard, our specific aims are to:

- Approach those families who participated in early intervention programs who have an extended family history of autism.
- Study as many affected and unaffected members of these families as possible. The participation of as many family members from the wider family as possible increases the amount of genetic information resulting in greater power for genetic analysis and a higher probability of gene discovery.

Contacts:

To participate in this study please contact:

Ms Shelly Thomas on 03 9905 1477 (leave a message) or 0409 959 895

Should you have any concerns about the project please do not hesitate to contact:

Prof Bruce Tonge.
Centre for Developmental Psychiatry and Psychology
Monash Medical Centre
246 Clayton Rd. CLAYTON Vic. 3168
Tel: 03 9594 1300

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

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).

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Treasurer (donations): Cathy Ryan, Vic.
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Teaching Language to Children with Autism: The Basics and Beyond

Dr Mark L. Sundberg, Ph.D., BCBA

Will present a 2 day Intensive

Applied Verbal Behaviour Workshop

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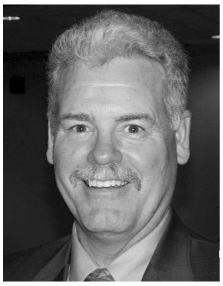

Mark L. Sundberg, Ph.D., BCBA is the pre-eminent world authority in the use of ***Verbal Behaviour* (VB)** in the treatment of children with autism and other developmental disabilities.

He received his doctorate degree in Applied Behavior Analysis from Western Michigan University (1980), under the direction of Dr Jack Michael.

Dr. Sundberg is a Licensed Psychologist and Board Certified Behavior Analyst who has been conducting language research with children with autism for 32 years. He works extensively with school districts in San Francisco, training schools in ABA/AVB.

He is the founder and past editor of the journal ***The Analysis of Verbal Behavior***, and is the co-author with James W. Partington, ***Teaching Language to Children with Autism or Other Developmental Disabilities***, ***The Assessment of Basic Language and Learning Skills: The ABLLS***, and co-author with Jack Michael**, *A Collection of Reprints on Verbal Behavior.***

He has published over 40 professional papers, given over 400 conference presentations and workshops. Dr Sundberg taught 80 college courses on behaviour analysis, verbal behaviour, sign language, and child development.

Dr. Sundberg has received a number of awards, including the 2001 ***"Distinguished Psychology Department Alumnus Award***" from Western Michigan University.

Workshop Overview

This workshop is designed for parents and professionals who are familiar with or interested in furthering their skills in *behaviour analysis* and the concepts from Skinner's analysis of ***Verbal Behaviour***: ***echoics, mands, tacts, and intraverbals***.

The first part of the workshop will present the revised assessment package designed to not only identify the strength of each verbal operant, but to identify specific language acquisition barriers that may affect an individual child's learning rate.

Many children with autism may be able to emit some *mands*, but often, a more careful analysis reveals that the *mands* are actually defective in one of several ways. Intervention procedures designed to ameliorate these language acquisition problems will then be presented.

Part two of the workshop will focus on barriers that may make it difficult to teach more advanced forms of verbal behaviour such as *RFFC*, *intraverbal*, multiply controlled responses, multiple responses (sentences), and *advanced manding*.

Several revisions of the verbal behaviour assessment and intervention program as described by Sundberg & Partington (1998) will be presented. The current revised VB assessment tool will be presented, together with the revised intervention program.

For more detailed workshop information see:
www.australiancentreforautismservices.com.au

Registration

Name
Organisation
Address

State Post Code
Phone
Email

* Students are required to provide student ID with registration
* An Administration fee of 10% will be deducted from registration fee upon cancellation
* No refund will be given after 22nd September 2006

Please forward payment to:
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Phone: (03) 9458 1333

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Refreshment & lunch will be provided

Free on site parking available