



Autism News



Griffin Piper with his mother, Katrina.
Photo courtesy of the Examiner Newspaper.

Griffin Piper is 8 years old and has an ASD. Griffin loves reptiles and has two blue tongued lizards as pets. Katrina, Griffin's mum, says however that he would really love a carpet python.

Katrina says that Griffin's interest in reptiles stems back to his time at Early Learning in Launceston, when he was introduced to lizards by a seemingly astute teacher. At the time Katrina says that Griffin was non-verbal, but she firmly believes that the reptiles were a catalyst to him learning to talk.

Katrina has supported Griffin's interest in things that creep and crawl and is very comfortable around the snakes herself (although not as at ease as Griffin).

Griffin's parents take him to the Lizard Club which meets only once every two months. At these events, Griffin is able to sit with the snakes and has slowly become more

comfortable with the other members in the group. Katrina says that when Griffin first attended the club, he was only able to stay in the room of forty people for five minutes at a time. Now he is comfortable being in the room for up to three and a half hours.

Katrina says that Griffin, who is home schooled, is well informed about carpet pythons. He has learnt how to handle the snakes and is aware of the rules for handling the reptiles safely. The snake is non-venomous, but Griffin understands that there must always be two people present when handling the it.

Katrina says that when Griffin is with the python, "it's as though someone has turned the autism switch off." However the law prevents Griffin having his own python and his exposure to the snakes is limited to his contact with the Lizard Club. Katrina is lobbying government to try and give her son greater access to carpet pythons. ✂

Welcome to New Members

Welcome to all our new members and thank you to everyone who has renewed their membership for 2008.

Charles Crowden Karina Zanchetta
Mary-Anne Vaz Kristen Desmond
Fiona Taylor

Please renew your membership today if you haven't already done so.

Thank you also to the many people who generously made a donation to Autism Tasmania with their membership renewal. Over \$1,000 has been raised.

We've not named each donor here, as we don't know whether people prefer public acknowledgement or privacy.☺

explore the opportunities, challenges and new developments for effective outcomes for young children, students and school communities



Working in Partnerships

11 & 12 July 2008
West Point Convention Centre
Hobart, Tasmania

www.workinginpartnerships.com

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'Autism News' is produced quarterly by a volunteer team led by Editor, Ros Ward.

Contact us at editor@autismtas.org.au

We welcome contributions from members on the many experiences and perspectives of the autism and Asperger's journey.

Commercial advertising enquiries for issue sponsorship, inserts or block ads are also welcome via this email address or the general enquiries number on the back page.

Disclaimer

The views expressed in *Autism News* and any enclosures are not necessarily those of Autism Tasmania Inc. Information is presented in the interests of providing a range of ideas and options for discussion and consideration. It does not imply endorsement by Autism Tasmania Inc.

From the Editor

The tragic events at Clifton Beach on 15 March gave us a poignant reminder of the fragility of life. While we may work hard to secure better resources or focus on the shortcomings or frustrations of services, it is the very personal and human stories that ultimately connect us.

Our hearts go out to the families and friends of Jack Kelty, his carer, Brendan Dermody, who disappeared on that fateful day and to the other young boy who was present.

These events generated a great deal of autism comment but as one letter writer asked — why does it take a tragedy to highlight autism?

Very timely, given that we have just marked the first World Autism Day and are leading up to Autism Month around Australia in May. As you will see in this issue, there is a national approach to Autism Month in 2008, with national activities, as well as related initiatives taking place around it in every state and territory, from many different sources.

For the second year, we'll be presenting the Alex Walley Awards as one way to recognise the contribution of people on the autism spectrum and the people working alongside them in so many walks of life.

In welcome news, Autism Tasmania has received \$50,000 interim funding from the Federal Government's *Helping Children with Autism* project, to boost its capacity to support early intervention initiatives from 1 July 2008. However, the funds are once off and must be spent by 30 June 2008. Governments must start playing their part with recurrent funding.

While the national boost in early childhood intervention funding is most welcome and long overdue, we must not forget that autism is a spectrum—the people in the community we serve have a wide range of capabilities, cover all ages and therefore have differing needs at different stages of life. It truly is whole-of-life.

An Active Voice

Geraldine Robertson's experience

The 2008 CEDAW (Convention for the Elimination of all forms of Discrimination towards All Women) Roundtable was held in Canberra on March, 31st. I was privileged to be selected to represent Tasmanian women who have disabilities and ASAN-AU, an Australian advocacy group for autistics. Our task was to inform a report on Australia's progress in eliminating discrimination towards women with disabilities.

I am sorry to say that in recent years many supports have been eroded. Policies such as Welfare to Work have caused hardship for many people with disabilities. All delegates commented on the difficulty of accessing financial support and services, but these are particularly difficult for many on the autism spectrum because of our autistic characteristics.

I was fortunate to be able to provide input into many aspects of Federal government policy making from the perspective of many autistic women who let me know of their concerns. Many levels of functioning & independence were represented in my discussion.

It was very noticeable that although we had similar concerns to many women, the specific issues which affect access to community life are very different for people on the autism spectrum. Several delegates said that they had never heard the perspective of autistic adults and stated that they hoped to hear more.

The important thing that I take from this is that we need to participate directly in all forms of policy making. ASAN is a strong vehicle for providing a united voice to promote the idea of "nothing about us without us" as we seek services that we really need rather than the services that we are perceived to need. ☞

Read more about ASAN AU on page 15.

Funding Boost Shapes Future

'Helping children with autism' interim grant

In its 15 years, Autism Tasmania has run without recurrent financial support from any level of government. While that hasn't yet changed, an interim grant of \$50,000 from the 'Helping children with autism' initiative will boost existing programs and provide a foundation for future services.

The same amount has been given as an interim grant to each of the eight state & territory autism associations around the country, to boost service capacity leading up to the introduction of longer-term initiatives on early intervention from 1 July 2008. There is no continuing funding.

While an attractive grant, spending the money by 30 June 2008 — just 15 weeks— presents some serious challenges for a small provider. The balance the Committee has chosen is to extend current services at a rate that can be sustained after the interim funding is finished, put money into activities which have a long-term impact and gather important information to assist service planning & public policy. We will be:

Extending the existing information and support to families, carers and people on the autism spectrum by employing a part-time staff member in southern Tasmania. We can respond more quickly to enquiries, provide more direct help and better support existing groups, as well as improve links with professionals and other agencies.

Engaging a person to gather accurate and up-to-date information about the full range of autism services, especially for young children with ASD, their families and carers. This includes access to diagnosis, post-diagnosis information and support, access to early intervention, transition to early schooling in both specialist and general settings. It will include a capacity assessment, identification of constraints on services, analysis of the specific needs of families and carers at this formative time and analysis of expected demand.

Completely re-developing our website. Much of the content is outdated or inappropriate and needs re-writing; the framework it's built on doesn't give the technical flexibility required to support the type of site we need. It will provide a long-term, low-cost, easily updated and readily accessible information service for a large section of the autism community.

Developing a full range of authoritative information & support materials for families, carers, people on the autism spectrum, other people in the field and wider community. We recognise that not everyone is able to or prefers to use the website, so this information will be more widely available at various places.

Setting-up a permanent office staffed with volunteers and some paid staff as an administrative centre and library, replacing the current donated office space at Giant Steps in Deloraine.

While this funding is a welcome boost, only recurrent funding will properly underwrite Autism Tasmania's activities and enable the planning necessary for comprehensive services to the autism community. ✂

Ross Divett Grant Success

Earlier this year, Autism Tasmania received \$4,500 from the Ross Divett Foundation, a national initiative of Centrelink staff.

This grant enables our Family Support Co-ordinator [or other staff] to better support autism interest groups, families and people on the autism spectrum in Circular Head, the West and East Coasts and the Huon Valley during 2008.

The funding will go towards direct visits to these centres, as well as indirect help via telephone or referral and resource materials to improve information and access to information for people in these locations.

Education Feature - 10 Alternatives to Suspension

For many parents of students who have autism spectrum diagnoses, the new school year is not one of anticipation of achievement and progress. Instead they hope desperately that this year there will be respite from phone calls to remove their child from the school. We all understand that principals have a responsibility to provide a safe working and learning environment for all members of the school community. Additionally, principals have an obligation to ensure that students have the right to an education which is enhanced, not compromised by the inclusion of students with significant differences. Frequently, suspension and exclusion from school are strategies used to promote these ideals. However, we know that exclusion rarely brings about changes in behaviour and therefore does not an effective agent for promoting our schools as safe learning environments.

Some schools are now using the principles of positive behaviour support to assist those students who experience ongoing incidents requiring discipline and/or suspension. In order to address these concerns, teachers are looking for consequences and strategies which do not limit the student's academic progress and which are more effective in bringing about changes in behaviour. The following is a summary of the article "10 alternatives to suspension" by Reece Peterson and may be useful for parents when advocating for alternative supports for students who experience severe behavioural challenges.

- Problem solving contracts remind the student follow a problem-solving process. The contract includes reinforcement for success and agreed consequences for continuing problem behaviors.
- Restitution permits the student to help to restore or improve the school environment either by repairing the results of misbehaviour or by improving the school environment in some other way.
- Mini-courses or skill modules can be designed to increase student awareness or knowledge about the problem behaviour.

Study methods would be varied and appropriate to the level of student functioning e.g. videos/readings, digital presentations/oral report. Topics would address the specific behaviour and could include drug abuse, social skills, anger management etc.

- Parents should be invited to brainstorm strategies that could improve their involvement in their child's education.
- Counseling from trained helping professionals e.g. school psychologist may focus on personal issues interfering with learning.
- Community service programs in which the student is supervised in for specified amounts of time can be created.
- Behavior self-monitoring. Self-charting of behaviors and feedback for the student can form the basis of reward programs for improved behaviour.
- Coordinated behaviour plans which are based on the results of a functional behaviour analysis of the reason for the target should be created. The purpose of a plan is to increase desirable behaviours and replace inappropriate behaviours.
- Alternative programming may include scheduling or curriculum content changes, opportunities for independent study or work experience programs. Alternative programs must be developed with reference to IEP goals and outcomes. In-school suspension should include academic tutoring, skill development which targets the behavior problem (e.g., social skills). In-school suspension should also include a clearly defined procedure for returning to class which includes achievable behavioural goals. It is important to examine the learning environment for factors which will result in the student using in-school suspension as a way to avoid attending classes. ☞

Reece L. Peterson is a professor in the Department of Special Education and Communication Disorders, University of Nebraska, Lincoln. The complete article can be found at <http://ici.umn.edu/products/impact/182/over5.html>

Autism Month - May 2008

Get involved!

Autism Tasmania's *Autism Month* Program

Throughout May - Gold Coin donation fundraiser circulating

Saturday, 17 May - **'Sensory issues & autism spectrum disorders'**

presented by Rose Clark

from 10am—3.30pm

St Giles Society conference room

65 Amy Road, Launceston

\$50 members/\$60 non-members

Saturday, 24 May - Alex Walley Awards presentation

Wednesday, 28 May - **Hit autism for six!!!** raffle draw

Help hit autism for six!!!

Autism Tasmania is raffling a cricket bat signed by current & legends Tasmanian Tigers players, donated by National Foods Australia and a Tasmanian Tigers shirt signed by batting legend, Michael Bevan, donated by the Tasmanian Cricket Association.

There are 1000 tickets only at \$5 each. This bat is a collector's item, so if you love your cricket, don't miss out! Books of either 5 or 10 tickets are available now. To sell a book or two or simply get a few tickets, call Carolyn on 6458 2096.

The raffle will be drawn on Wednesday 28th May towards the end of Autism Month. Please help us to **Hit Autism for Six!!!**



Go for Gold!!!

We will again be conducting the very successful Gold Coin donation program throughout the of May. To raise awareness of Autism during Autism Month, we would love as many of these donation sheets to be out in the community as possible. Would the school your child attends accept one? Or perhaps your local store, newsagent or chemist may be happy to help?

Donation sheets fit very nicely around an empty 'Pringles' potato chip cylinder and a slit can be cut into the plastic lid for the gold coins. Shopkeepers may be happy to have a cylinder in their store as they look neat and take up very little counter space. If one sheet is filled in, another can be put straight over the top. So please **Eat Pringles for Autism.** Contact Carolyn on 6458 2096 or email admin@autismtas.org.au for further information. ☺



Alex Walley Awards 2008

Celebrating Achievement in ASD

In 2007 the inaugural Alex Walley Awards were launched. The awards were established to honour Alex's memory following his sudden death some years earlier. The awards are presented in two categories to recognize achievement. Category one recognizes an organization or individual who has made a significant contribution to the field of ASD while category two acknowledges achievement by a person with an ASD.

The awards had a very successful beginning last year with many nominations of outstanding quality. Mike and Sue Walley (Alex's parents) are looking forward to a similar response this year. ASD is often portrayed in the media in a very negative manner and the awards are one way of celebrating the positive events occurring within the autism community in Tasmania.

Nominations are now being sought for the 2008 awards which will be presented on Saturday 24th May. Please consider those you know who have an ASD and note their achievements, big or small which are worthy of nomination. Alternatively, we encourage nominations for teachers, schools, allied health professionals (doctors, speech pathologists, occupational therapists, etc), disability service providers, support workers, etc who have made an outstanding contribution to ASD in Tasmania.

Nominations must be completed on the official nomination form which is included in this mailing. Contact Rose Clark on 6423 2288 or Mike Walley for further information or email:

autism@autismtas.org.au

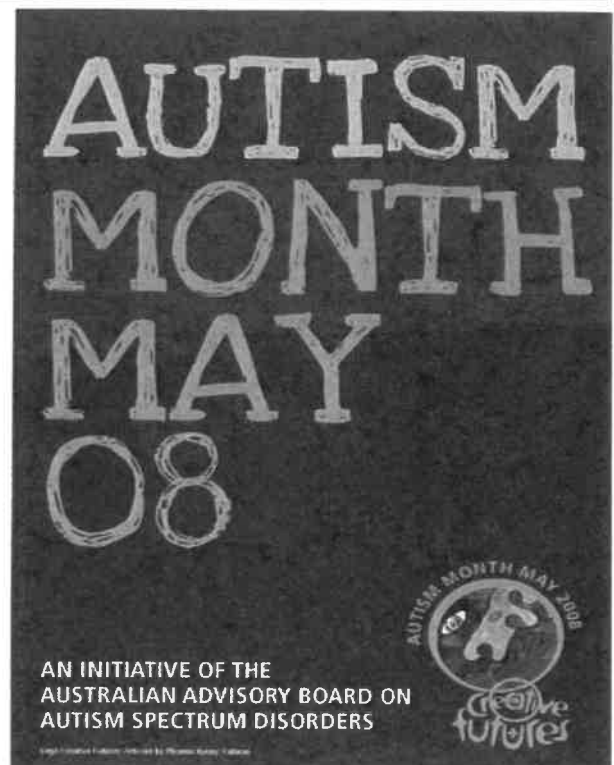
This is the design being used by each of the state and territory autism organisations around the country to promote Autism Month in May 2008.

It combines the new 'month' - replacing the previous Autism Awareness Week - with the banner *Creative Futures*, which featured last year and will be continued as a theme throughout 2009.

The Australian Advisory Board on ASD decided to continue a theme over more than one year to help build theme awareness and enable groups to plan projects around a consistent theme well in advance.

Posters and postcards are being produced and will be appearing throughout May, supported by a range of activities throughout the country.

Each state & territory will be presenting their autism awards at this time. ☺



A New Logo for Autism Tasmania



The new logo for Autism Tasmania is designed to provide a fresh, attractive and memorable image for the organization.

The use of visual signs and symbols to identify a group has a long history, including the well known heraldic devices of medieval times, but the practice stretches back for millennia. For instance, the rulers of Macedonia in the 3rd century BC, from whom Alexander the Great arose, had a stylized sunburst for their logo. In our times, the University of Tasmania has recently adopted a lion as its corporate logo.



3rd Century BC
logo of the
Macedonian
Rulers



The logo of the
University of
Tasmania

The logo is a badge, a visual cue that is

immediately associated by the observer with the organization. Therefore, the main target of the logo is not the organization itself so much as the rest of the community. As soon as a person catches sight of the logo they should think of the organization, not necessarily because the image gives direct information about the organization – we have words for that – but because the association has been made over time. To this end, the logo must be distinctive and attractive: distinctive so that it stands out and will be associated with the group; and attractive so that positive associations are made in the mind of the observer.

The new logo meets the criteria of distinctiveness and attractiveness. This new symbol will help us with marketing and fundraising that is so necessary to maintain our information, training and family support services.

Autism Tasmania is proud to announce the launch of its new logo in Autism month. We would like to thank Brad Allen of Scarab Design for his graphic design work. Our new logo, based on the rare Rainbow sun orchid (*Thelymitra polychroma*) a plant endemic to Tasmania, symbolizes the difficulties and joys of ASD. As with orchids, with appropriate care and nurturing, those on the autism spectrum can blossom and develop their full potential, positively contributing to their families and communities. ☘

Volunteers for Agfest

We need your help for a whole day or part of a day. Free entry to Agfest, so come along & help and see Agfest.

Required is a set-up crew on Wednesday, 30 April; and sales teams on Thursday, Friday & Saturday, 1, 2 & 3 May 2008.

This year will be our biggest ever Agfest -due to major order system changes currently going on within National Foods, we'll be running 3 sites plus the milk route at Agfest - the entire milk operation!

We won't be packing or selling product bags this year because of the order system changes but we'll still have plenty to do. **Call Mick Clark on 0417 354 157**

Relationship Development Intervention ® [RDI]

Relationship Development Intervention evolved from the work of Dr Steven Gutstein, who is based in Houston, Texas. Dr Gutstein believed that advances in autism interventions had not kept pace with autism research and set out to devise a 'systematic clinical program to address the core problems faced by individuals on the autism spectrum.'

Libby Maher is a Certified RDI Consultant and conducted a two-day workshop in February for the staff of Giant Steps. Libby was Foundation Principal of Giant Steps, Sydney, so has a good insight into how RDI can fit in with a more traditional approach.

Libby talked about the 'missing skills' which a typical child of six months acquires so easily but are not adopted by a child with autism. Dr Gutstein and the RDI proponents believe that these skills are teachable and are essential for future success in the complex environments of real life.

Much of RDI is involved with developing 'quality of life'. Statistics show that even the highest functioning people on the spectrum are at risk for failure in life. A National Autistic Society (UK) study released in 2001 showed that only 12% of high functioning adults with autism were employed, only 3% could live independently and over 65% had no social contact outside their family.

RDI believes it can remedy the core deficits of autism and provide a better quality of life for both high- and low-functioning individuals. In their literature, core deficits are defined as:

- Social Communication
- Relationship building
- Motivation
- Critical Thinking
- Abstract language comprehension
- Problem solving
- Executive functioning

The RDI Program was first devised for parents and the family is still the main focus of the intervention. Certified consultants work with families to implement strategies and offer supervision and counseling to achieve the

agreed goals. However, there are implications for the classroom and Giant Steps is implementing three primary focus areas: Emotion sharing, Social referencing, and Coordinated Actions. The aims are:

- Create motivation for the students to orient to the teacher,
- Develop students' attentiveness to facial expressions and increase awareness of non-verbal communication,
- Maintain attention to speakers and stay focused on the speaker,
- Reference when uncertain by seeking out facial expressions and non-verbal actions of adults,
- Co-ordinate actions by adjusting behaviour to regulate with adults.

RDI does not replace other interventions; rather, it provides a new way of looking at interactions with the students.

Dr Gutstein believes that RDI is evolving and points to new understandings which have been adopted as research continues. For example, there is a new focus on the development of Episodic memory which uses a different neurological pathway to the more common Semantic Memory. Semantic memory deals with recognition, procedures, and so on. Episodic memory allows an individual to link memories with emotions experienced at the time.

The website www.rdiconnect.com provides more information. Libby can be contacted at libbymaher@bigpond.com ☎

Donation Thanks

To Terasa Brinton and the team from Business Affairs Branch, Consumer Affairs & Fair Trading, Dept of Justice for their donation from a plain clothes day held in March.

Stories from the Field

Sharing ideas about what works

This summer, I headed off for a big adventure. My family had decided that it would be a good idea to have a family Christmas with my paternal family in the United Kingdom. My brother was already living in London with his wife, and my parents were travelling to Europe in September for their bi-annual holiday for Dad to compete in the World Masters Athletics Championships, then for a tour of another part of the globe to tick off on mums' list of places to see. The plan was for my to join them in Britain when I finished work for the year. It all sounded good in theory.

I have Aspergers Syndrome and experience a lot of anxiety. My only previous independent trip was for a University residential school on the mainland. A delayed departure on the way home left me turning in circles in the middle of Sydney airport, humming and tapping my fingers. Not a good omen!

We started planning this latest trip well in advance. My mother took me to the travel agent to find out what support would be available to me. I was able to order bland meals, request an aisle seat, and alert the airline staff to my disability. The aisle seat was chosen as I have a fear of being 'squashed', trapped in a crowd without an easy escape, and I would find it difficult to intrude on other passengers to get in and out of my seat. My doctor prescribed diazepam for just in case. I don't usually agree to use tranquillisers, but they do have a purpose. I prepared a folder containing not only my tickets and passport, but a letter from my doctor and all my prescriptions, along with the small alert card created by the adult autism group. Mum helped me create a packing list before she left, so I knew exactly what I needed to take and only had to tick off each item as I packed it.

SUITCASE

4 x socks
2 x bra
5 x undies
2 x trousers
2 x jumpers
2 x thermals
hankies
1 x shoes
3 x skivvies
1 x good shirt
2 x nighties
extra pills
sponge bag - shampoo,
- conditioner,
- soap,
- manicure set,
- itchy cream,
- comb,
- razor
- powder
- tissues
sheet sleeping bag
pillowcase
hand warmers
coat
drink bottles
hot water bottle

Vital items included cheese sandwiches and crisps, just in case my idea of bland food didn't correspond with the airlines' idea. A fortunate precaution as it turned out – who would want to eat chicken sprinkled with birdseed? Or scrambled eggs with mushrooms? And all the bread provided was wholemeal, which my irritable bowel can't tolerate, and I forgot to mention when ordering the meals. I found that I could purchase bottles of water after passing through security, so that I could board the plane with them. This made it a lot easier than constantly asking for more water to make up my usual 2-3 litres a day.

I took the soft toy who always shares my bed in my carry on luggage. I was prepared with a puzzle book, electronic crossword

Travelling and Asperger's Syndrome

solver, ipod with audio books, a science magazine and a book. The audio books were essential as it was impossible to take enough reading material to last a 23 hour trip – I read a book in 2-3 hours. Of course I also had all the usual things – toothbrush, anti bacterial hand wipes, fresh underwear, hairbrush etc.

ON BOARD

face washer & soap
deodorant
toothpaste & brush
hairbrush
towel
undies
socks
computer
Ipod
magazine
scrabble
drink bottle????
food, sandwiches, chips
pill box & puffers/spacer
prescriptions
back cushion
rain coat, hat, gloves
jumper
camera
handbag
wallet, diary
hankies
peekaboo (soft turtle toy)
papers/passport

I had a list of times, places, people, what to do etc. My aunt dropped me off at Hobart airport, seeing me through security (we had several practice runs at this before the departure date), and making sure the airline staff were aware of my disability. Virgin airlines were fantastic. They checked on me several times prior to boarding, pre boarded me so I could avoid the crowds and showed me how to call for assistance.

The problems began when the flight was delayed due to bad weather in Melbourne.

I knew my cousin was waiting for me and was anxious that she would give up and leave. Of course she didn't, and she helped me collect my bags, replenish my supply of cheese sandwiches and check in with Emirates.

Problem number 2. When explaining my disability to Emirates check in staff and asking if I could be pre boarded etc., I was told that "we don't offer that service".

Problem 3. My cousin could not accompany me past customs, and no one had warned me about this so it wasn't on my list. I got through customs ok, and found the gate I thought I needed to be at. There was a long wait here, and none of the support that I had from Virgin, so, anxiety rising, I took the diazepam. Despite this, I found myself in the middle of a crowd while boarding and had a panic attack. This actually prompted the staff to realise that there might be a problem, and they had me wait until the end of boarding instead of going on when my section of plane was called. A lovely Irish lady returning home, a physician who actually knew what Aspergers was, waited with me, and checked on me during the flight.

I survived the flight very well - thank the Lord for the pharmaceutical companies!, and even slept for much of it. Transfer at Dubai meant more crowds and more diazepam, but I was still ok. This time they called for passengers needing assistance to pre board, so I did. Again, I survived the flight, although my digestive system was reacting to the stress and I spent a lot of time in the loo.

On arriving at Manchester, I discovered another problem with my list. It said that Mum and Dad would meet my at the airport. They forgot to tell me that I had to go through immigration, customs and baggage collection first. Immigration wanted to know my address while in the UK, and I didn't know it. All I could tell

Stories from the Field — continued

them was 'my aunts' house in Cumbria'. Fortunately that sufficed, and I was through customs. The next problem arose at baggage collection. I waited ... and waited ... and waited ... and panicked. No bags. The flight was already late landing and I wanted my mum. By this time I was beginning to hum and turn circles, when the Irish physician intervened. She sat me down, and had an airport official come to me with the forms, and got him to page my parents to get contact details so that my luggage could be sent to me when it was located. It turned out to be sitting on the tarmac in Dubai, along with the gear of everyone else who had travelled on that flight from Melbourne.

A three hour drive later, I was able to shower and go to bed for 13 hours. My luggage turned up at 6 the next evening. The rest of the trip was fairly easy in comparison. My parents know how to keep me calm, and plans for each day were made in advance so I could write them in my diary. We visited lots of zoos and animal parks. We met lots of people too, but you can't have everything. London was probably the most difficult place – it was very big, crowded and noisy, with constant sirens from emergency vehicles and cars honking. It didn't help that I stayed with my brother who gets a lot of pleasure out of teasing me, and telling me all the violent crime statistics for his area and similar things. My sister-in-law makes up for him though. We didn't schedule enough down time into the itinerary which meant that at times my anxiety levels were higher than they should have been.

My advice for autistic travelling is visual schedules. If you are like me, then write everything down, and try to prepare for alternatives eg. Sometimes luggage goes missing. If this happens, you speak to an official at the airport. You need to fill out a form, describe your luggage and tell the official where you will be staying. Make sure you get a reference number. Speak to people who have been where you are going before, or travelled on the same airline.

Make the airline staff aware of your needs. If you are a parent with younger children, or more severely autistic children, make visual schedules with photos, pictures from magazines etc. If you contact the airline in advance, they may be able to send you an in flight magazine that will have pictures of your plane, the uniform your stewards will wear etc. Some Velcro or bluetack with some spare symbols for the unexpected might help eg, line up, wait, alarm (security alerts). If your child is a fussy eater, take food. Prepare with activities that your child likes and can do in a confined space. If they are sound sensitive, take headphones. Emirates had a wide selection of movies to watch, but if your child has a favourite, consider purchasing a portable DVD player. If your child has behaviours that may attract attention, you may like to have a card to give to airline staff explaining autism, and any action you would like them to take or avoid. Think about where you are best seated – near the window so your child can't escape, or on the aisle where he/she has a bit more space. Try to schedule rest time into your itinerary.

Overall, I enjoyed most of the trip, and it was a positive experience. I finished feeling proud that I had coped as well as I did. Would I do it again? Probably not. Certainly not 6 weeks of travelling, but maybe a shorter trip." ✂

Sarah Stevenson

ON THE PLANE

I can ask for water when I need it.
I can eat my own food.
I can ask for help if I need to.
I have medication if I need it.
I will meet mum and dad in Manchester
I don't need to stress
Keep Calm BE A TURTLE

For the uninitiated, turtles pull their head in and pretend they're not there if they don't like what is happening around them.

Like Minded Company

Attending conventions

Over the past few years I've been doing something that's a bit unusual for a person who's as uncomfortable with crowds as I am: I've started attending conventions. The first one was the inaugural AI-Con. Held in 2006, it was the first anime convention held in Tasmania. Anime, for the uninitiated, is a catchall phrase used to describe animated entertainment produced in Japan. Then, in February last year, I travelled to Melbourne to attend a convention named Nullus Anxietas, (mock Latin for 'no worries') a gathering of people who are fans of the work of author Terry Pratchett. Most recently I've been to the third AI-Con and I am in fact finishing this article after coming home from the last day of the convention.

The first time I went to a convention it was simply as an opportunity to thoroughly immerse myself in one of my dominant interests. I hardly need to explain the appeal this held for someone with Aspergers syndrome. I was so focused on the material aspect of the convention that I gave no thought at all to other aspects of the situation. Strange as it may sound it didn't quite register with me that I'd be spending the entire day surrounded by a large number of people who would all be there for exactly the same reason as me, and with whom I shared a major interest. Or rather, the implications of the situation didn't register with me.

I'm generally a little uncomfortable in group situations, although as someone who has a high-functioning ASD I can usually manage it well enough, especially in an environment where my own role is clearly defined. And yet, the thing that has struck me about every convention I've been to is the complete absence of any discomfort on my part. This despite the fact that on the surface a convention about a personal interest should be

everything I'm least adept at handling: A purely social environment (which means there's no defined role or function I can comfortably fit into) with a large number of people who are mostly strangers to me. The reason, I believe, for the lack of my usual unease in such circumstances is the absence of its underlying cause: The feeling of having no connection to and nothing in common with the people around me. The sense of not belonging.

While it's true that just having one shared interest with a person (or a group of people) hardly guarantees you will immediately become friends, it does establish valuable common ground. But at a convention it's more complicated than that. To start with, the convention itself acts as an informal screening process. When I show up at a convention about anime/Terry Pratchett/whatever, it is with the understanding that everyone else there is not only interested in the subject matter but that their interest in it is comparable to mine. Otherwise, why would they even be there? (In fact, the first AI-con attracted people from all over the state and a handful from the mainland, while Nullus Anxietas drew attendees from every state in Australia and several from overseas). On top of all that, if you put a bunch of anime fans or Terry Pratchett fans in the same room you automatically have a group of people who are amused, interested and excited by the same kinds of things – one shared pastime can sometimes say a lot about someone's personality. So in actuality you have a group of people who may have quite a lot in common, even if they've never met before.

This all seems very straightforward and obvious as I write it now (as I'm sure it must seem to you) but as I said a moment ago it wasn't something I gave much thought to before I attended a convention for the first time and the security I derived

Stories from the Field — continued

from it was completely unexpected. Looking back, I believe this was largely because I simply couldn't conceive of being so comfortable in the presence of so many strangers – I'd long ago resigned myself to never possessing the level of self-confidence necessary to achieve that level of comfort. I'd never imagined a situation where the unwritten, instinctive rules of human interaction that I tend to trip over or blunder through were modified to the point that I could interact with other people as easily as (I imagine) ordinary people do. But at a convention the common interest I know I share with everyone else present creates a framework I can work within to bridge the gap that normally separates me from others (or keeps me from trying to connect with them in the first place). In this specific context, I *do* know the rules and it's an exhilarating feeling.

Another factor is the size of the particular cons I've been to, which hasn't been more than a few hundred. That's significant, because it places me squarely in the comfortable zone where there are enough people around for me to feel safely anonymous but not so many that I feel intimidated or overwhelmed. Nonetheless, it is remarkable thing is just how willing I am to step out of that comfort zone at the conventions I've been to. People who know me in other circumstances would be more than a little surprised by the talkative extrovert who enjoys hamming it up for the crowd – and is pretty good at it, too. Truth be told, I am often still surprised by the things I've found the courage to do at any of the conventions I've been to. For someone who once skipped class to avoid making a two minute presentation to twenty people, performing in an off-the-cuff comedy skit for an audience of a hundred or so is a fairly dramatic step forward. But at the most recent AI-con that's exactly what I volunteered to do when I agreed to perform in a parody of 'Spicks and Specks'. I got my fair share of laughs, too.

Another example of this confidence comes from the Nullus Anxietas convention, when I

personally staged an impromptu comedic episode. One of the attendees had dressed up as an Orangutan - a reference to a character who works as a librarian and is magically transformed into an Orangutan in the first novel of Terry Pratchett's Discworld series. This forms the basis of a running joke in which the Librarian (as he is known) - who retains many human sensibilities - is frequently mistaken for a monkey and invariably responds with violence to the misidentification. Just before the quiz night on the last evening of the convention a large number of people were milling about in the foyer of the convention centre and the man in the Orangutan suit was moving around on all fours amusing the crowd. I realized that it was a perfect opportunity to set up the monkey joke for real. After a moment's hesitation I pointed at him and cried out "Look! It's a monkey!" In the spirit of the joke he howled in mock outrage and proceeded to chase me around the room, which everyone present found entertaining, judging by their laughter. I was able to do this because in that context I had something that I wouldn't have possessed anywhere else: Knowledge of how other people would react. I knew, with complete certainty, that everyone else would understand what I was trying to do. I knew that everyone would get the joke.

It comes back to what I said about knowing the rules – the unwritten ones that govern so much of human interaction and which I never seem to entirely understand, even when I think I do. When I go to a convention I enter an environment where, for at least a little while, this is not the case. Therefore the stress that usually accompanies dealing with new people, or large groups of people, disappears. Because we're all there for the same reason, because we all have at least one important thing (important to those present, that is) in common, something rather special happens: I get to feel just like everyone else. It's a good feeling. ☞

Ben Gardner

ASAN—Autistic Self Advocacy Network

**Members of the Australian autistic community who have long been involved in self advocacy have formed ASAN AU (AUSTRALIA), an affiliate chapter of ASAN:
www.autisticadvocacy.org**

About ASAN in America

The Autistic Self-Advocacy Network (ASAN) is a non profit organisation run by people on the Autism Spectrum, those with other unique neurological types & neurotypical family members, professionals, educators & friends.

ASAN was created to provide support and services to people on the autism spectrum, as well as change public perceptions & combat misinformation by educating communities about people on the Autism Spectrum.

About ASAN AU

ASAN AU is run by Australian Autistic adults who have been involved in self- advocacy for a number of years and invites membership from autistic and Asperger youth and adults who wish to receive support to engage in self-advocacy. ASAN AU understands the following:

- Autistic citizens are capable of contributing to society and enriching the lives of their families and communities.
- While Australian society provides supports and accommodations for many of its citizens, there is little understanding of the specific needs of autistic children and adults.
- Autistic adults want be involved in the planning of services to be used by themselves and their peers. Inclusive and equitable services can only be developed when stakeholders contribute positively towards promoting their own wellbeing and connectedness to society.
- Autistic adults want recognition of the fact that autism is a life long condition that impacts both positively and negatively upon a person's ability to function in society.
- Autistic adults recognise that a proactive stance means that the thousands of children in early intervention and education programs now will hopefully inherit a more effective system and a more understanding community.

Autistic adults need support in the following areas — Communication, Sexuality, Cultural Identity, Accommodation, Healthcare, Crisis Management, Education, Criminal Justice, Advocacy, Employment & Socialisation.

The extent to which autistic adults are & have been ignored saddens ASAN AU members. All Autistic citizens are capable of contributing to society and enriching the lives of their families and communities but need the support and acceptance of society as a whole.

An investment in the future of people with Autism is an investment in the skills and talents that are untapped by virtue of this group being a silent demographic. ☞

Stepping into program series now open

Applications are open until 23 May 2008 for this series of programs providing final year university students with disability the opportunity to gain practical, paid work experience in their field of study.

An initiative of the Australian Employers Network on Disability, it covers accounting, law, banking & information technology.

Although positions are all in mainland capital cities, its an interesting initiative that you may want to find out about:

Google: **2008 stepping into programs**



The Black Balloon

Written & directed by Elissa Down

Starring: Toni Collete, Erik Thomson, Rhys Wakefield, Luke Ford and Gemma Ward

Writer/director Elissa Down's debut, *The Black Balloon*, is a heart-warming and powerful film that deals with what it is like to be different, and the difficulty of trying to fit in.

The film centres around 15-year-old Thomas (Home & Away's Rhys Wakefield) who has moved to a new school and just wants to fit in. Making it hard is his severely autistic older brother Charlie (Luke Ford).

Much of the film's success is due to the cast. As the boy's mother Toni Collette is, as always, brilliant in her ordinariness. Heavily pregnant, her devotion to both her sons is beautiful and painful to watch. Her army husband (former All Saints actor Erick Thomson) never succumbs to ockerish stereotypes as he juggles to deal with his demanding family.

Jackie (Supermodel Gemma Ward) is a pleasant surprise. Her beautiful yet alien features make her seem out of place in suburban Brisbane, but she is both delightful and funny to watch. It is impossible to watch the development of the innocent childhood romance between Jackie and Thomas without remembering what it is like to be 15 and in love.

Brilliant acting alone can not make a film. Writer/director Down has drawn on her own experiences growing up with two autistic brothers to poignantly illustrate the demands autism places on a family. Thomas is torn between loving and hating his brother. Unable to talk, Charlie is constantly embarrassing Thomas, from

rubbing his own excrement into the carpet to putting a tampon in his mouth.

One of the most enjoyable aspects of this film is its inherent Australian-ness. Set in suburban Brisbane in the early 1990's, this is one of the first films to capture this era and it does so with subtlety and without falling victim to Aussie clichés. Watching it is like turning back the clock a decade, from the bright pink stackhats to the daggy fashions - Blinky Bill cartoons and super nintendos help transport the viewer back into a daggier decade.

The Black Balloon is an incredibly strong film. Families are built upon love/hate relationships and everyone can relate to being embarrassed by a family member. For anyone with a personal experience of autism, this film will be especially moving. The sacrifices the family makes for Charlie are amazing and the film is laden with love and humour.

The end of the film had me laughing and crying simultaneously - no easy feat. *The Black Balloon* deals with a hard, and rarely touched upon subject and does so without trivialising or stereotyping autism. Viewers will leave entertained and hopefully with a greater understanding of autism and the challenges families face in dealing with it.

Laura Crowden

(Laura has an adult cousin with autism).

..... and Books

Growing Up with Autism –Working with School-Age Children and Adolescents, R. Gabriels and D Hill (eds)

An excellent book which focuses on how to assist families to move beyond the early intervention stage to address children's multiple care needs through puberty and the transition to adulthood. There are strategies for either the individual with ASD or his/her family to use community resources to address behavioural, social, language, communication, mental and physical health, sexual, legal, family leisure and educational needs. The authors argue that despite early intervention, many individuals with ASD still have significant impairments which can lead to long term behavioural and emotional dependency which must be addressed.

They claim that the most significant predictor of later outcome appears to be the level of intellectual functioning in childhood (IQ >50 and language attainment by age 6 years.)

The book's multi-systemic therapy model is derived from family systems theory which is all about inter-connectedness.

There is a very good questionnaire which is photo-copiable – a child and caregiver information form.

Regarding sexuality, it argues that "a sensitive, individualised approach to addressing this developmental transition is best".

Despite its US focus, the chapter on family holidays/leisure is excellent.

With adaptive lifeskills, the authors advise teaching to maximise independence, not learned helplessness, they suggest classroom activities to embed social interactions and emphasise positive behavioural support. They argue that teachers need 15 minutes of educational planning time for every hour of intervention!

They also address criminal justice issues and remind us that social naivety can lead to exploitation.

1001 Great Ideas for Teaching and Raising Children with ASD's

by Ellen Notbohm and Veronica Zysk

The authors are a parent and a professional and they claim to offer pages of "try-it-now solutions" that have worked for thousands of children. The authors regard sensory integration along with communication and language therapy as the two main issues to tackle. The authors also optimistically advise that we need to love the individual with ASD absolutely and unconditionally, "a child who feels unconditional acceptance and perceives that the significant adults around him truly believe that 'he can do it' has every chance of becoming the happy, competent adult we always hoped and dreamed he would be".

Other chapters have great practical suggestions to:

1. address behaviour as a form of communication and what to do about tantrums,
2. daily living strategies – including haircuts, dressing, siblings, hospital, birthday parties, sleep, safety, death...
3. relationships
4. education
5. the law (US)

The authors put a powerful case for the extension of school year services into the holiday breaks in order to maintain gains.

This reader gained the impression from this book that IEP's, parents rights and teachers rights are better served in the US than in Australia.

Lisa Minchin reviewed these books and has advised Autism Tasmania that they are available from the ACD library. Contact ACD (Association for Children with Disability for further information. You do not need to be a member of ACD to borrow from their library.)

Rose's Tips

Visual Strategies - Why Use Them?

Rose Clark is Family Support Co-ordinator with Autism Tasmania. She is also an Autism Consultant with the Department of Education.

Teachers and parents all over the world use visual strategies which include schedules and timetables. Why use visual schedules in the first place? Many people with an Autism Spectrum Disorder have difficulty with shifting attention, difficulty with attending to foreground sounds and shutting out background noise as well as auditory processing problems.

What are visual supports?:

- Schedules
- Checklists
- Activity scripts
- Choice boards/menus
- Calendars
- Personal stories
- Homemade stories
- Behaviour scripts
- Cue cards

Visual schedules are essential because:

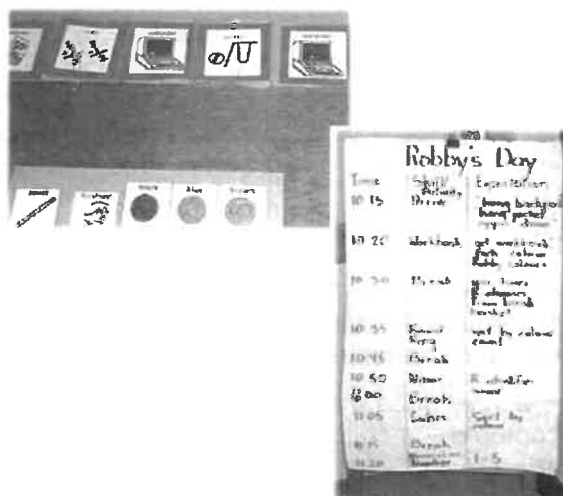
1. I have time to stop, look and listen to what you are telling me
2. I can look at the picture whilst I work out the message
3. I remember things I see much better than things I hear

Schedules help people with ASD to:

- Follow routines
- Cope with change
- Reduce stress
- Increase independence
- Develop an understanding about what's happening – daily, weekly, monthly etc.
- Teach about changes in routine
- Give choices
- Support transitions
- Teach new skills
- Manage time
- Teach new routines
- Share information

Visual schedules can use photos/pictures/remnants or words OR a combination of these. A visual schedule/timetable does not have to be complicated or difficult to organise – you might like to begin with a carpet square with the photos (or whatever you've decided to use) which have the 'hook' Velcro on the back which will stick directly to the carpet.

A useful free website is: www.do2learn.com There are free pictures which are great for social stories as well as visual schedules.



Some examples of visual schedules

Rose will be presenting a seminar on visual schedules in Devonport on Sat 21st June and in Hobart on Sat 28th June - come along and see practical examples.

Each issue we will be seeking useful tips from professionals. If you have anything you would like to see covered, please email: editor@autismtas.org.au or call the general enquiries number on the back page.

Inside the back page

A quick look at some of the latest information in the autism community ~

Minister Meets Autism Groups

Autism Tasmania representatives were one of several stakeholders in the autism field that met recently with the Minister for Education & Skills, David Bartlett MHA.

In the hour that we had independently with the Minister and his education advisors, we were able to brief him on Autism Tasmania's role and talk in detail about the gaps we're finding in education practice and outcomes for students on the autism spectrum.

We will be meeting again in the near future and in the meantime, will be providing him with a detailed picture of the experiences that we have gathered from parents of students throughout Tasmania, across the age range, at different levels of functionality and including the often overlooked experiences of students with Asperger Syndrome. ✂

Disability Services Review

Committee members Penny Cromarty & Roger Law attended different regional briefings by consultants KPMG explaining the recently released draft Summary Report of the Review of Disability Services.

The report provides a concise snapshot of the funding shortfalls and regional inequities within the existing Disability services funding allocations and addresses the key challenges facing the service, DHHS and the government in its allocation of resources and application of public policy. The consultants propose a very different funding and service management model to address the problems identified.

You can read the full report at:

www.dhhs.tas.gov.au/agency/hs/disability/review_ds.php ✂

New Tassie Autism Group

A new autism group — Action for Tasmanian Autistic Children [ATAC] has been formed in Tasmania to lobby State & Federal Governments. ATAC is spear-headed by [Secretary] Roger Law, who has helped a number of families in crisis in the last couple of years.

More information at: www.atac.biz/atac ✂

NSW Autism Funding

The NSW Government recently announced \$6 million early intervention funding which is estimated to support 660 children between two and six over the next 4 years.

\$4 million will be spent on targeted, 20-week programs for pre-schoolers and services run by special education teachers and therapists at centres and in homes.

As part of this, Aspect will receive \$2.2 million to expand its successful BUILDING BLOCKS early intervention program;

\$1.2 million will go towards a new childcare centre in Western Sydney, run by AEIOUI, which already runs 5 centres in Queensland;

\$500,000 will go towards training staff to work in early intervention services; and

\$200,000 to produce a DVD & manual for families of young children who have just been diagnosed with autism. ✂

NAS Campaign

The National Autistic Society in the UK has recently launched their **think differently about autism** campaign. There is a special emphasis on adults on the autism spectrum.

Go to the campaign website for more information:

www.think-differently.org.uk

*Information & Support
Training & Consultancy*

Contact ~ Rose Clark

Phone: 6423 2288 Fax:
6423 1086
Mobile: 0407 320 048

General Enquiries & Library

Phone: 6362 4755
Email: admin@autismtas.org.au
Postal: PO Box 1552

Newsletter

Email: editor@autismtas.org.au

Regional Autism Support Groups Meeting Regularly
always check before attending when a meeting date falls in school holidays

<u>Area</u>	<u>Meeting Location</u>	<u>Date & Time</u>
Circular Head	Rural Health Centre Emmett Street, Smithton	Usually 3 rd Wed each month 10.30 – 12pm <i>Call Carolyn Moore - 6458 2096</i>
Brighton Autism Mother's Group	Brighton Primary School 27 Downie Street, Brighton	Every 2 nd Wed morning 9 – 11am <i>Call Keitha Duncombe—6268 0698</i>
Cressy/Longford	Cressy District High School Main Street, Cressy	Last Friday each month 3.30 – 4.30pm <i>Call Natalie Hill – 6397 6327</i>
George Town	Wattle Building Agnes Street, George Town	Last Wed each month 7 – 9pm <i>Contact Rose Clark</i>
Lilydale/Exeter	Alternates between the areas	Last Friday each month 10.30 – 12pm <i>Contact Rose Clark</i>
Hobart	Tascare 231 Main Road, Moonah	2 nd Thurs each month 7.30 – 9.30pm <i>Contact Rose Clark</i>
Asperger Syndrome Support Group [Hobart]	Tascare 231 Main Road, Moonah	Last Sunday each month 2 – 4pm <i>Contact Rose Clark</i>

Autism support groups also meet in Penguin, Devonport, Launceston, East & West Coasts & Huon Valley from time to time. Call Rose for details.