



Autism News



A perfect day for members of the Hobart Adult Asperger Support Group enjoying a picnic lunch at the Botanical Gardens recently.

On July 30th 2005 six people attended the first meeting of the adult Asperger Syndrome group in Hobart. During the preceding 12 – 18 months I had received numerous calls from people with Asperger Syndrome and some from others who suspected they fitted the criteria. I'd also had calls from various service providers asking about services for adults with Asperger Syndrome. It was because of these calls that the initial invitations were sent out.

The group is now in its third year and each meeting has a focus which those attending have been instrumental in deciding. The topics have been many and varied and there have also been two guest speakers, including a yoga teacher.

Group members are working on a booklet on Asperger Syndrome to distribute to the wider community to promote better understanding of the difficulties experienced by people with the disorder. They have also produced a credit card-sized hand-out card for group members, which explains Asperger Syndrome to people reading it.

Meetings of the group have been held monthly and continue as such, with the size of the group gradually expanding – at one get together we had 18 people! (This included some extended family members who came along as support, which was wonderful.)

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*Membership renewals now due
- see insert & note on page 2*

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Members of the Asperger Syndrome group decided very early on in their time together that a support person (a friend, family member, support worker) was welcome at the meetings, if it meant that the person with Asperger Syndrome would come along. The age range of those who come along is extremely wide which is wonderful as there are many experiences to share.

The last get together of 2007 was a lovely picnic in the Botanical Gardens in Hobart on 25 November, which many of the group attended. It was a perfect day weather-wise and the time together was greatly enjoyed. The group will meet again in January 2008.

I feel very privileged to be involved with this group of exceptional people. ☺

Rose Clark - Family Support Co-ordinator

Welcome to New Members

Jenny Marshall
Sari O'Meagher
David, Melanie & Maya Rowe
Pat & Bruce Durant
Sharon & Neville Jolly
Cynthia Murphy
Carolyn Stubbs
Helen Guy

Thank you to everyone who has joined as members in 2007 – our membership now stands at 161 individuals, families and organisations, with perspectives ranging from people on the autism spectrum, parents, extended families, carers and professionals working individually or in a range of service organisations.

2008 membership renewals are now due

Most Autism Tasmania memberships end on 31 December, so we've enclosed renewals with this issue. Please pay as soon as possible. If not renewed by 31 March 2008, your membership ceases and you won't continue to receive information about what's going on in the autism community locally, nationally and beyond, nor have discounted access to family workshops, seminars or conferences.

You haven't received a renewal if you joined as a new member from October onwards, have already paid for 2008 or you've received a complimentary membership.

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.

'Autism News' is produced three times each year by a volunteer team led by Editor, Rose Ward.

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

For commercial advertising, please use the general enquiries contact on the back page.

From the Editor

Welcome to the second issue of the new look *Autism News* and my first as Editor. Thanks for the positive feedback about our August issue and the enthusiastic response to our request for your stories about what works or doesn't—and why. We've published two more stories from parents in this issue.

With these changes, our thanks goes especially to former Editor, Cheryl Scott, who has sourced articles and produced the newsletter for many years, often under very tight deadlines and difficult circumstances.

It's an exciting time in autism, with the announcement of the Federal Government's *Helping children with autism* initiative for early intervention and schooling, which is explained in detail in the following pages. But problems remain at other important transition points, as the following article on SIP funding shows for young people moving from full-time schooling to the adult life and the world of work.

We all have opportunities to put our views and experiences forward as part of the ongoing Disability Services Review. There's a quick update on the inside back page or you can go directly to Disability Services on:

www.dhhs.tas.gov.au

You'll also find profiles of our Committee and staff, following the 2008 AGM. Its membership renewal time and your renewal form is enclosed. Full details are on the opposite page.

From all of us involved with Autism Tasmania, we hope you have a safe, happy and relaxed Christmas, New Year and holiday season. ☺

Ros Ward

SIP Funding Farce

Once again, parents of young people with autism and other disabilities are confronting uncertainty in 2008 as SIP funding fails to meet people's needs. The struggle to plan

for an already difficult future continues.

According to the Department of Health & Human Services website, "*The Supporting Individual Pathways Program provides assistance to young adults with disabilities as they make the transition from school to adult life.*"

Not for most applicants. According to estimates, less than 45 of more than 90 applicants received funding. To quote a Disability Services representative "there were too many applications and not enough funding."

The same response was given 12 months ago when applicants missed out or were paired to stretch funding, limiting peoples' options in the process. In 2008 there are young people whose SIP funding applications have been denied, as priority was given to first-time applicants. They are now left in limbo during one of the most crucial transitions in their lives.

Transition from school to adult life for young people on the autism spectrum is a huge step but with support over time can be successful. It requires understanding from Disability Services that 1 or 2 years partial support is insufficient; that parents need secure long-term support to plan their child's transition needs.

Parents are constantly informed by Disability Services that there is inadequate funding. Enough is enough. The Minister—Lara Giddings—and the Lennon Government must be held accountable for a "crumbs from the table" approach to disability funding. ☹

If you're having difficulty with SIP funding, contact Advocacy Tasmania on:

[South] - 6224 2240

[North] - 6331 0740

[North West] - 6434 6475

Alternatively, contact Speakout on:

[South] - 6231 2344

[North] - 6343 2022

[North West] - 6431 9333

Helping children with autism Federal Government initiative underway

In early October, shortly before the Federal Election was called, announcements from both major parties made autism an election issue for the first time.

On 3 October 2007 the then Prime Minister, John Howard, announced the \$190 million package *Helping children with autism*, to be funded over 5 years, with services starting on 1 July 2008.

This was a project announcement, not an election promise, so work started immediately across three Australian Government departments.

On the same day, Opposition Leader, Kevin Rudd and spokesperson on family services, Jenny Macklin, announced that Labor will set up specialist child care and early intervention services — six in the initial stage — for children with autism if elected to Government.

Adrian Ford, Chair of the Australian Advisory Board on ASD [AAB-ASD] met Senator Jan McLucas, Labor's spokesperson on ageing, disability & carers on 5 October. She confirmed that if elected, Labor would implement John Howard's plan as well as their six centres of excellence in the field of early childhood. No detail of the centres of excellence plan was provided.

Under the \$190 million package, the Australian Government will provide:

- New Medicare funded services to diagnose ASD and provide early intervention, including speech pathology, occupational therapy and psychology services;
- Early intervention services for approximately 15,000 families of children aged up to 6 diagnosed with ASD, including playgroups, behavioural therapies and intensive programs;
- Education and support programs for families and carers of children aged up to 6 with ASD and the development of an ASD website;
- Support for up to 5,800 parents and carers of school-aged children with ASD, through workshops and information sessions in city and rural locations;

- Professional development for 1,800 teachers and other school staff to support school students with ASD to help them improve their learning skills; and
- 20 childhood autism advisors located across Australia to assist parents and carers to find the best services available to meet the particular needs of their child. Prior to the appointment of the childhood autism advisors, existing autism stakeholder groups will be provided with early support funding to build their capacity to provide support to families.

While the detail of these initiatives will unfold as consultation and implementation advances, some clues of specific initiatives can be found in the media releases, website downloads and letters to Autism Tasmania and other autism agencies around the country.

For example, part of the \$116.1 million earmarked to ensure greater access to a range of early intervention services is said to include:

- Access for eligible children of up to \$8,000 in services over two years for more structured & intensive early intervention services, including one-on-one intensive activities, behavioural therapies & tailored group & individual programs; and
- For severe ASD, up to \$20,000 of individual assistance over two years, to contribute to costs of intensive early intervention services.

ASD will include autism and Asperger's syndrome, as well as other less prevalent developmental disorders. \$20.7 million allocated over 5 years will see new Medicare items for:

- Paediatricians and child psychiatrists to diagnose and develop a treatment plan for children aged to 12 years, on referral from a GP;
- Developmental psychologists and speech pathologists to assist with the assessment, where required; and
- Specific allied health providers to provide early intervention following diagnosis [providing up to 20 services per child].

Implementation & Consultation

The Departments of Families, Housing, Community Services & Indigenous Affairs [FaHCSIA], Health and Ageing [DoHA] and Education, Employment & Workplace Relations [DEEWR] - are working together to implement the package.

It is expected that all components of the project will be operational from 2008, with most initiative planned to start from 1 July 2008.

Each of the three agencies has specific responsibility for parts of the initiative. An Interdepartmental Committee [IDC] including the Office of Prime Minister & Cabinet, meets regularly to ensure the overall delivery of the project. Broadly:

- FaHCSIA oversees the implementation of education and support for families & carers and increased access to early intervention for children aged 0—6 years.
- DEEWR is responsible for the teacher & school staff professional development and the parent & carer workshops & information sessions.
- DoHA is responsible for development and implementation of the Medicare funding initiatives and direct payments to families.

FaCSIA has established a consultative forum called the Implementation Advisory Group [IAG] to provide direct stakeholder advice. This group meets monthly. The AAB-ASD has two representatives on this group, along with Bob Buckley from A4. Other autism service providers, such as The Lizard Centre in Sydney are also involved.

DEEWR has held a stakeholder forum with representatives from each of the state autism associations and education authorities plus the non-government education sector and peak education associations and organisations.

DEEWR Request for Tender

In mid-December, DEEWR advertised nationally inviting "submissions from suitably qualified organisations or consortia of organisations to undertake a project to improve the educational outcomes of school-aged children with ASD".

Submissions were invited for either or both of the two components — professional development for teachers and other school staff who work with students with ASD; and workshops & infor-

mation sessions for parents of school-aged children with ASD.

The closing date is 31 January 2008. Not surprisingly, various organisations are looking at this tender, both separately and as consortia.

The Reasons for the Package

Many groups and individuals have lobbied both sides of politics for many years to have autism taken seriously. Both major political parties drew from similar sources to support their plans.

The DEST [now DEEWR] Information Sheet quotes from the former Autism Council of Australia [now AAB-ASD] report released in March 2007, 'The Prevalence of Autism in Australia'. It refers to Centrelink data which gives "an estimated prevalence of ASD across Australia of 62.5 per 10,000 for 6—12 year old children. This means that there is one child with ASD on average in every 160 children in this age group which represents 10,625 children aged between 6 and 12 years with an ASD in Australia."

From a Synergies Economic Consulting study, 'Economic Costs of Autism Spectrum Disorder', released in April 2007, preliminary estimates were made of the annual economic costs of ASD in Australia as between \$4.5 and \$7.2 billion. The costs included general and mental health care; social services; education; employment; informal care and the impact of wellbeing, referred to as the 'burden of disease'.

The Information Sheet went on to say that "providing help and support to these children early in their lives will make it easier for them to attend school and participate in everyday life as they grow older. Unfortunately, few Australian children with ASD can gain access to effective early intervention and many teachers lack the skills required to handle the demands of educating a child with ASD."

Find Out More

The *Helping children with autism* Inquiry Line is 1800 289 177.

Using the internet, Google *Helping children with autism* and choose the FaHCSIA site or go direct to www.facsia.gov.au and click Individuals, then Disabilities, then follow the news item link. ☞

Introducing the Committee & Staff for 2007-08

The Autism Tasmania Committee consists of 10 positions – a President, two Vice Presidents, a Secretary [also the Public Officer], a Treasurer and five Ordinary Committee Members. Under the Association's rules, at least two positions must be filled from each of the three Tasmania regions – north, north west and south.

Members of the Committee are elected for two year terms. Consequently about half the positions fall vacant each year.

At times the question is asked "Who are these people on the Committee?" We've endeavoured to answer this question with a short profile of each Committee member and our Family Support Co-ordinator. As you'll see, their skills and experiences are wide and varied - all make a valuable contribution.



Penny Cromarty is in her second year as President. She is married with three children, of whom the eldest, Anna, 20, has autism. Penny is a former teacher and now works for W.A. Cromarty and Co, an engineering and IT company in Launceston.

Penny was involved with the establishment of Giant Steps at Deloraine, a Board member for several years and Chairman for two. She was an inaugural member of the Disability Services Ministerial Advisory Council and is now a member of the Premiers Disability Advisory Council.

She is particularly interested in exploring and implementing improved programs and services for young adults with disabilities in general and autism in particular. Penny believes that Autism Tasmania facilitate support for families and work with governments and service organisations to ensure that the needs of the autism community are recognised and met.

Penny is active in her children's schooling and hobbies and is often at the yacht club helping out while her other children sail. She enjoys reading, swimming, travelling and being with people. ☞

Senior Vice President, **Dr Andrew Davies** is a Lecturer in Physiology in the School of Human Life Sciences at the University of Tasmania in Launceston. His research interests include the development of cardiorespiratory control and the neurophysiology of sleep. Current projects include the effects of different forms of exercise on sleep in the elderly and cardiovascular risk factors in obstructive sleep apnoea.

He was born in Melbourne and grew up on the Mornington Peninsula and this produced an enduring interest in sailing and nautical history. After graduating from Monash University, he went to Sydney to teach at the University of NSW medical school where he won the Vice-Chancellors award for excellence in teaching and then went to teach at Sydney University, gaining his PhD.



For several years he was a Fellow of St Andrew's College within the University of Sydney. There, he was involved in undergraduate and postgraduate teaching, developing and implementing a Masters program in Reproduction and Genetics and the first Masters program in Sleep Medicine. During this time he was working on the development of medical technology. One of the projects, a cardiac assist device, is due to enter clinical trials in heart failure patients in the USA shortly.

Andrew is married to Louise Reid Davies and they have three children. The family moved to Launceston in March 2003 and Andrew and Louise joined Autism Tasmania soon after. Their eldest son is autistic and currently in secondary school in Launceston. Andrew is interested in promoting Autism awareness and professional development in the health care sector. ☞



Vice President, **Ros Ward**, moved to Hobart this year with her family after living in Launceston for many years and where her two children, the eldest of whom has autism, had grown up. Her son had his 21st birthday in June.

This is Ros's second term on the Committee after previously being a Committee member from 1992-1996. She was also on the steering committee to establish the Giant Steps Centre and then a Director on the Board for several years.

Ros's son is now an adult and faces a whole new range of challenges ahead, particularly in terms of employment/day support options etc. She looks forward to this year, particularly with the Federal Government initiatives announced before the November election.

Ros works part time as a teacher with the Education Department and sees the inclusion policy at work first hand! She enjoys editing the newsletter and welcomes contributions from members, particularly positive stories. She is also involved in the presentation of the Alex Walley Awards and hopes these will become highly valued within the autism community. In her spare time Ros enjoys reading, spending more time with her extended family, renewing old friendships in Hobart and making new ones, and being able to walk on the beach again! ☞

Neil Gardner lives in Hobart with his family and is the parent of an adult son with Asperger Syndrome. Neil spent his paid working life in the Commonwealth Bureau of Statistics before retiring four years ago. He's now busier than ever!



Now in his fourth year as Treasurer, Neil is a keen golfer and fisherman. He is also the licensee of the New Town Bay Golf Club (another voluntary position).

As Treasurer it is Neil's responsibility to ensure that Autism Tasmania meets its financial and legal responsibilities. This has required him to undertake training in MYOB software and to come to terms with the GST. He is extremely grateful to David Savill at Giant Steps for his unwavering support in his early days as Treasurer when he was trying to find his way. He feels one of his greatest achievements is having the accounts better prepared for the auditor each year, therefore reducing the auditor's account! ☞



Mick Clark was re-elected for a second term as Secretary and Public Officer at this year's AGM. He joined the Committee in 2004, after 11 years with Giant Steps Tasmania, where he held a variety of leadership roles in the original project team, then the inaugural Board and later in the day-to-day management of the Centre. He is a Director and past President of the Australian Advisory Board on Autism Spectrum Disorders [formerly the Autism Council of Australia].

Mick lives in Devonport, is married to Rose and they have a 20 year old son, Thomas, who has autism and is presently making his way through the difficult transition from full-time school to the world of work and other adult activities.

He advocates a whole-of life and whole-of-government approach to autism services. In his other life, Mick runs a consulting business specialising in organisational change, leadership & communication. ☞

Peter Hatters lives at Westbury with his partner, the multi talented and beautiful Julie and 14 year old daughter Imogen, both on the spectrum. He has been associated with Autism Tasmania for a number of years as a member and later as a Committee Member. It was twelve years ago that Autism Tasmania assisted Peter's family on the diagnoses trail.



Peter believes that 2008 looks to be a very positive and busy one for Autism Tasmania particularly with the funding on offer by both Labor and Liberal parties. The priorities are to continue to lobby Governments on all levels, to promote the need for further funding. He would like to assist our young children and disadvantaged older persons with autism gain access to services, and support for their particular needs, whatever they may be.

Peter would like to see more emphasis placed on our children within the education system so that they have the opportunity to gain the social intelligence required to live as contributors and responsible members of their communities. School only lasts for a short time so Peter feels we must ensure that it is not wasted. Peter also believes we have a responsibility to assist our children gain meaningful and fulfilling employment.

As an Employment Consultant Peter knows that once the obstacles impacting on people have been carefully addressed, much sustainability and economic and personal wellbeing can be achieved for the majority of people with an ASD working within the community. Peter hopes that his experience will assist Autism Tasmania and others to meet their goals, improve their skills, abilities, knowledge and attributes and be happy living in their community. ☞

Sue Brown [not pictured] has been a Committee Member for several years and recently retired as the Tasmanian nominee on the former Autism Council of Australia's Professional Committee, which among other things selects research grant for the Apex Trust for Autism each year. Sue is a speech pathologist who lives in Launceston with her family. ☞



Carolyn Moore filled a casual vacancy on the Committee at the beginning of 2007 and was elected to the Committee in her own right at the 2007 AGM. She lives in Stanley with her son Samuel. Their home is at the edge of the village, with The Nut at its back and Sawyer's Bay to its front. They enjoy beautiful, natural scenery and tranquility - very Asperger's friendly!

Carolyn is interested in all things alternative and 'new age', particularly holistic health, energy dynamics, numerology and astrology and she likes to incorporate these interests into mosaic designs.

Carolyn is a student at Smithton TAFE where she studies Information Technology and is hoping to put her learning to good use while on the Autism Tasmania Committee through contributing to the newsletter and possibly the website.

Carolyn lived in ignorance of the Autism Spectrum until a few years ago when Samuel was diagnosed with Asperger's. She wants to learn as much as she can and help to raise awareness of ASD. She has been on the committee for just one year and is still finding her feet, listening and learning from those with more experience. She plans to participate in the peer support program and is being weaned into leading the Circular Head Parent's support group who meet in Smithton. ☞

Roger Law was elected at the 2007 AGM as a Committee Member. He is a grandfather who cares for an autistic grandson. After numerous court appearances he was able to gain the first fully Government-funded ABA program for his grandchild. With this success, Roger last year began representing other families with autistic children who were in crisis. He appears in children's and magistrates courts on behalf of these clients and represents them in meetings with politicians and government agencies. He welcomes contact from other families in similar circumstances— feel free to call him on 6286 1316. ☞



Louise Reid Davies was elected as a Committee Member at the 2007 AGM. She has a Bachelor of Arts from Monash University and a Graduate Certificate in Museum Studies from the University of Leicester.

Louise was founding Museum Director/ Curator of the Westpac Banking Museum, promoting and managing the museum and within the Marketing and Corporate Relations Division. In this role she developed business banking, fostering relationships building with corporate and retail bank clients.

Louise was Curator of the Historic Photograph Collection, managing and raising the profile of the Collection within the University. She has also been a freelance curator and art consultant to Westpac Banking Corporation. Louise has extensive experience in marketing, education and exhibition management.

She is the parent of a 14 year old son who is on the autism spectrum and lives in Launceston. ☞



Rose Clark, Autism Tasmania's Family Support Co-ordinator — and therefore an employee rather than Committee Member — has filled many roles in her continuous association with Autism Tasmania since it began in 1992. In this segment, she too explains a little about herself.

I am a Tasmanian, born 'a very long time ago' according to one delightful lad I recently had the pleasure of meeting. I grew up in Deloraine when it wasn't the interesting hub it is now and moved to Launceston to train as an early childhood teacher. I loved teaching (and still do) and it took me to many interesting places where I met wonderful children and parents.

I became involved with Autism Tasmania in 1992 when I attended the first meeting in Launceston when my son Thomas was about 5 years old. I have been continuously involved in one guise or another ever since.

About 5 years ago I became the first employee of Autism Tasmania. As the Family Support Co-ordinator part of my role is to offer support and information to parents, carers, people on the spectrum and their families. To ensure that parents were being catered for many groups were established around the state and it is through these that I have had the privilege to meet and talk to so many wonderful, resilient and innovative parents. I thoroughly enjoy my visits to the various parts of the state to talk and meet with families.

My role with Autism Tasmania also involves providing information sessions and training for organisations around the state and while this can be challenging I find it very interesting and invigorating to meet people mostly working at the 'coal face' who care very much for those they provide services for.

To finish off I'll let you into some secrets, I really love music and have varied tastes — I also used to sing with an all female singing group. I enjoy cooking and am interested in a good wine to go with whatever dish that makes its way to the table. Having a meal with good friends is a lovely way to spend some free time. I am also particularly fond of dark chocolate and find it very hard to resist. The one activity I don't get nearly as much time to do is gardening which really is a passion and one which I find extremely relaxing. Finally the people that can help make all this happen in my life is my own family which is the very reason I began this journey in the autism world in the first place. ☺

Rose Clark

Family Support Co-ordinator

is on annual leave from Christmas to the 2 February 2008.

Phone and email messages will be checked regularly and urgent matters responded to by Autism Tasmania.

Hobart Show Thanks


Our sponsorship relationships with National Foods is an important part of our fundraising program. At the Hobart show in October, we raised over \$1800 through milk sales— while a good result overall, the final day was marred by a disappointing crowd, which meant hard work for our volunteer crews moving all the stock at discounted prices.

Our thanks once again go to 12 students from The Friends School, to Autism Tasmania members Carol Webster & Keith Heard, Rowena Wilkinson and her son Finn and friend Emma & Angela Derrick from Holy Rosary School. A special thanks to Neil Gardner, Mark Ward and Mick Clark who planned, set-up and co-ordinated daily deliveries and stock throughout the 4 days of the Show.

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Stories from the Field

Sharing ideas about what works

Whether we're people on the autism spectrum, parents with young, adolescent or adult children, carers or professionals working alongside, we've all discovered things that work and don't work.

Here are another two wonderful stories where people share ideas about what works for them, their kids, their family or the person in their care, as they travel the autism journey.

I WILL NOT COME TO NEW ZEALAND

At the request of my daughter, I have used a pseudonym to protect her privacy.

Last time we went on our bi-annual trip out of Tasmania (in 2005) it was a nightmare for our eight year old daughter with (then) undiagnosed high functioning autism. When we visited the exciting places that we had looked forward to sharing with our children, Seaworld... Australia Zoo... it was torture for her. Too many people. Too loud. Too long... "I want to go home. I just miss my chooks too much." When we did return to Tassie after ten days away, Roxy declared "I'm never going on a holiday where you have to catch a plane again. It's too far and I don't like it".

In February this year Paul and I decided that this time we would take our children on a special holiday to New Zealand for three weeks, including a week's skiing. When we shared this joy with our children, ten year old Roxy was appalled. "There is no way", she declared, "I am not coming and you can't make me and I won't do it. You will have to go without me".

Whoops.

We were a little dumbfounded. We'd budgeted for our holiday; we knew we could afford to do some unusual and fun things together. We'd be together as a family for three weeks, and Paul had been to New Zealand before and knew we'd all love the natural beauty and the rich variety of outdoor pursuits available. What was wrong with Roxy?

Questioning her didn't really reveal anything. She just plain didn't want to go. A dear friend offered to have Roxy for three weeks so that we could go without her. That was tempting. It would certainly be an uncomplicated holiday with just two easy-to-please children. But NO, that is not what we had planned. A family holiday is a family holiday.

We made the executive decision to be the parents, told ourselves it was okay for us to make a hard and fast decision and Roxy would have to come with us. Together as a family we would make it work. We decided that if everything turned pear-shaped and Roxy was not coping with the constant change of travelling that we would stop where we were, buy some board games and just enjoy being together. Obviously we did not want that to happen so we started to plan for a happy holiday.

First of all we thought about the things that Roxy enjoys. Physical activity, being outdoors, animals, knowing what is going to happen, being in control, and being with her family. Easy. What creates stress for her? Crowds, noise, cities, sudden change in plans, feeling pressured to do things that she doesn't understand, constant change...

We started to collect some brochures and books on New Zealand, focusing on finding out about the things Roxy enjoys. We stopped talking about the fact that we were going there and did not indulge Roxy in conversation about her not coming. We

simply looked at the facts, what was there. All of the children love skiing so one of the first things I did was to contact the Mt Cardrona Ski Resort and make some enquiries about their Skiwees Kids Program. It sounded brilliant, just what we were looking for, so I booked all three children in via internet.

A booking confirmation arrived, "Dear Roxy", it began. It explained all about the program, what was involved, what would be needed, what would happen. Imagine my excitement and the excitement of each of our children as they read their individual letters. They couldn't wait. That was step one in the right direction.

We tried to plan to have extended stays in some places, so that Roxy had a bit of free time to wander around looking for lizards, or poke holes in the ice with a stick or whatever she needed to do. As we made firm plans, I printed out information and photos from the net, and collected yet more brochures from The Flight Centre to cut up. I found an old exercise book and made it into a "day to a page" diary for her, covering the three weeks we would be away.

Together Roxy and I began to build up a reverse travel diary, not what we had done but what we planned to do. We cut out pictures of the apartments we were to stay in, the car we were to hire, even the breakfast menu of our first night's accommodation. As we pasted events into their appropriate days, we discussed what might happen. We purposely left a few days blank, and I wrote "A free day. What will we choose to do today? with a list of ideas that we might choose from. Sometimes I cut out information about the area we would be staying in and wrote "I wonder if we will choose to do any of these things..."

We talked about the fact that we hadn't booked accommodation for times we could be flexible, but nights such as the day we arrived in New Zealand were organised. I tried to explain everything, and talked a lot about what other people do when they are on holiday and what we

have done on previous holidays. "We won't always know where we are going to sleep, but we will all be together and we will have fun because we are together."

When Roxy expressed concerns and worries, we had the travel diary to refer to. I never downplayed her fears, but affirmed them for her. When she said she would still feel nervous about catching the plane and would worry that we will miss it, I comforted her by explaining that many people feel like that before they catch a plane and that people do miss planes. I explained that we would be getting up early enough to make sure that we had plenty of time to get to the airport, even if we had a puncture we should still have enough time! I added "And if we do miss the plane, then we will buy a good book and take turns reading to each other to fill in time until we can catch the next one." I just kept on saying it, "Whatever happens, we'll be together and we'll have fun.

Gradually Roxy's enthusiasm grew. We were very aware that her fears and anxieties are very real for her and that this trip would be a huge challenge but we had decided that she is too young to opt out of life and that we will do all we can to support her in having as many rich and varied experiences as possible, while making life feel safe for her.

WE DID GO to New Zealand as a family, all five of us. Roxy was very anxious the morning we left, with typical anxiety symptoms. She hated the noise of the engines on the plane, especially when landing. Going through customs, collecting our rental car, finding our apartment; these things are a necessary evil for the most seasoned traveller and the preparation and planning that we had done made the world of difference.

We had the most fantastic, refreshing, family bonding holiday imaginable. The children loved the skiing, after four days of lessons they were using the lifts and tows and skiing the beginner's runs all over the mountain. We did some great bushwalks, went indoor rock-climbing, went in mazes, tunnels, trains, jet-ski

Stories from the Field – continued

Sharing ideas about what works

boats. We saw heritage buildings, and wild animals, ate takeaways and at restaurants. Roxy LOVED IT.

Our plan to have quiet days every now and then and to include lots of outdoor activities and physical challenges really paid off. Our reverse travel diary changed everything. Each of the children enjoyed being able to check what was coming up next, or where we were headed to.

It would have been such an easy choice to leave Roxy behind, and it was so much extra work to prepare her but it was worth every moment. It was such a huge success with so many far reaching consequences. Roxy learnt that it is possible to overcome a fear, and life can be so much fun. When I recently asked our children when they would like to go back to New Zealand, Roxy was the first to answer. "TOMORROW." ☘

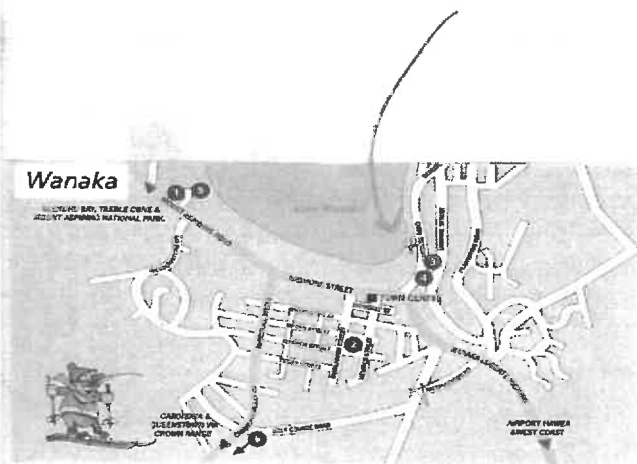
THE SEEMINGLY OBVIOUS THINGS THAT WE TOOK THAT MADE LIFE EASIER FOR ROXY

- ◆ A cot sized quilt from her room which she could wrap around herself, snuggle under, or lay over the linen provided in a bed to make the bed smell right.
- ◆ Familiar storybooks from home to use to continue our snugly bedtime routine.
- ◆ Normal comfortable clothes rather than special dressy ones for the holiday.
- ◆ Familiar soft toys to cuddle.
- ◆ A backpack with Roxy's sketchbook, pencils, and activity books, and electronic game.
- ◆ Non perishable snack food and bottled water, so that basic needs could be met immediately.
- ◆ An emergency prescription from the paediatrician! (Which we did not need).

..... a page from Roxy's diary

Sunday 15th July

Our apartment is here, on the edge
of Lake Wanaka.



Wanaka



PANORAMA COURT

Apartments,
29-33 Lakeside Road,
Wanaka

Phone 0800 433-554
03 443-9299

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Stories from the Field – continued

Sharing ideas about what works

My Sammy - Natalie Hill

As a first time pregnant mother, the first thing I wished for was a healthy happy baby with ten fingers and ten toes. Sam was born in 1991, I was 23 years old. There were a few problems, it was a hard long labor with forceps used to drag him out, but he screamed and had ten fingers and toes so I was happy.

My second wish for Sam was that he would have a good time at school. I had a very sad, lonely time at school so it was a big wish.

In 1996 I gave birth to my second child Marc and Sam started Kinder at Norwood Primary School. He was a very good little boy if he understood what was expected of him. The teacher had a bit of trouble understanding him and often had to piece what he was saying together after all the words were out to understand his meaning. I have always been strict with Sam and some might even say too harsh – but in public he was and is well behaved, he has and shows good manners and his once cheeky get-him-anything grin has matured to a devilish smirk.

During his prep year Sam was identified with Semantic Pragmatic Disorder by the Speech Therapist, this disorder is associated with Autism, so that was my first official introduction to Autism.

In early 1998 I realized Marc was displaying similar behaviors to Sam with one difference, No Real Words. After the assessments were done Marc was identified as ASD.

At this stage I made a life choice and left the boy's father. In 1999 Sam started grade 2 at Longford Primary School. As I had moved back to my old home-town I was familiar with some of the teachers, in particularly Sam's grade 2 teacher, so I

explained that Sam had some problems and she really seemed to listen. However our move meant that he had gone from a school with Speech Therapy time to a school with No Speech Therapy time allocated to him. In the State Education System there are too many kids and not enough support staff for kids to access appropriate and timely assessments and therapies.

By the time Sam reached grade 5 he was struggling with the school work – he still got confused with the alphabet. Marc had started kinder when Sam was in grade 4. As a result of Marc's earlier diagnosis, he was picked up by the State Education System one year earlier so therapy was a priority in Kinder. I was having some great contact with the Speech Therapist at Longford and she made sure Sam's follow-up assessment was completed.

At the same time the Guidance Officer and the Speech Therapist were trying to find some way to get funding for Marc, it came out that the boy's father had South Australian Aboriginality in his blood lines, so that was the answer to our problem. Both boys were entitled to aide time and both boys required extra support to keep up in class.

In 2003 when Sam was in grade 6 I gave birth to my third child, Emmi-Lou, Sam was and still is very protective of her. The transition from Primary to High School was difficult, although I had tried to get some extra orientation for him and I let Kings Meadows High know he was coming. However, apart from some after-school tuition, Grade 7 was not good a good year for Sam. Scholastically he didn't improve much and one day he took beer to school to try and make school more tolerable.

By January 2005 we had finished building our new house in Cressy – yes another change. With all of our moves and changes I have always tried to have the kids involved. For example when I started

seeing my current husband – Sam was not happy!!! The trick was to find out what would make him happy....Some toys to play with. Not his father, as I had suspected.

The move to our new house saw the boys in separate bedrooms decorated their way. We had talked up the move in a positive way for both the boys and it worked. They both wanted to get to their new school. Sam settled down into his new school very well with the help of the Rural Co-Pilots program.

There appeared to be no trouble with Sam until one time when the school clown/bully tried to choke Sam. Sam came out of this confrontation upset in case he had really hurt this boy. Straight away I rang the principal to find out what had taken place. Yes, I was told, the boy in question had gone home after being in sick bay, but there were to be no consequences for Sam as nothing had been reported.

At the end of 2006 I was told by a couple of teachers that they wanted Sam for SRC, I laughed and told them he would like to be an extrovert but he was too much of an introvert so good luck. I was right, Sam never campaigned so was not elected.

All his school life Sam's end of year results had been 12-18 months behind age appropriate. This trend started to change in grade 9 and by grade 10 he had 'caught up' and then surpassed age appropriate. I have always been an interfering mother, so for parent/teacher interviews I made sure that his teachers knew he could have difficulties and what to look for.

All the teachers he has had at Cressy District High School have been great, they have worked with Sam and assisted him to become a valuable member of the community. After telling me all year he was not doing the leavers dinner, he did. He didn't do the Red Carpet but snuck in the back door, the staff were pleased to see him attend, as was I.

At the last assembly, Sam was awarded the *M & L Badcock Memorial Prize for Thoughtfulness and Willingness to Assist*

Others and for two years in a row Sam was *Best and Fairest for Soccer*.

I have always known my Sam is a beautiful person and now I know other people feel this way also.

Next year sees Sam head off to Newstead Collage this will be interesting as Sam HATES buses and we live in Cressy, however his Godmother lives in town and we will do whatever it takes to get him there because I know once he is there he will apply himself and succeed.

Sam is aware of his autism, he doesn't like it and hates me talking autism all the time, the flip side of this is that he loves me and is proud of me for helping him. Our relationship has evolved into a great mother/son working relationship.

I am very proud to have Sam as a son and wish him all the very best for his future. ✂

Share the highs, share the lows. Tell us what works for you. Don't keep your stories or ideas to yourself!

Send your tip or story to us so it can be shared. Short is great because we can fit more in, so please keep it to about 600 words or so plus any pictures or diagrams that help the explanation.

If you want to comment on this story, we'd love to hear from you as well. Space is limited, so please keep it brief.

Email is best to:

admin@autismtas.org.au

If you can only send a hard copy then post to:

*'Stories from the Field'
Autism Tasmania Inc
PO Box 1552
Launceston TAS 7250*

Autism Tasmania - 15 years on

Reflections from Two Past Presidents

Autism Tasmania celebrated its 15th birthday in October 2007. To get a sense of how the Association and 'autism' has progressed, we thought we'd seek some personal perspectives from two past Presidents, both members of the founding group.

Mark Ward

1992 - 1996

Mark was elected the inaugural President of Autism Tasmania in 1992, after being instrumental in establishing the organisation. Mark's son was diagnosed with autism in 1991, at a time when autism was rarely heard of in Tasmania, and there were certainly no autism specific services. Following the diagnosis of his son, Mark and his wife made contact with Autism Victoria seeking information. As a result and with support from Amanda Golding at Autism Victoria, a meeting of Tasmanian attendees at the National Autism Conference in Melbourne in September 1992 was convened, and a decision made to form a Tasmanian association. Mainland associations had already been in operation for 25 years and it was clear that Tasmania was lagging far behind in recognition of autism and service provision.

Mark felt he could do much more for his son if he collectively got together with others rather than just pursuing his own son's needs. 15 years on and Mark is pleased that Autism Tasmania is still operating and looks back on some achievements with pride.

Mark was heavily involved in the joint approach to the Tasmanian Government by Autism Tasmania and the Giant Steps Steering Committee. This resulted eventually, in the Giant Steps centre opening in Deloraine in 1995, after much lobbying and considerable hard work. This was all done in Mark's spare time, while working full time as an Engineer. It involved many

late nights (and early mornings) and all in the days before email!

Mark feels that the positive changes of the past 15 years include a much greater awareness of autism, and notes that finally refrigerator mothers are no longer mentioned as a cause of autism (thank goodness). He believes that the development of knowledge, skills and experience of professionals working with people with autism has added to the autism landscape in Tasmania. However he still sees issues with inadequate numbers of trained professionals such as speech pathologists etc and believes this will continue while these courses are not offered at Tasmanian Universities.

As his son is now an adult, life has moved on but new issues face his family. Dealing with Disability Services has been frustrating at times. There also seems to be a high turnover of staff within many service providers within the disability field and Mark questions the reasons for this. Is this a result of poorly paid positions, difficult working conditions or both? Mark has also noticed that there is less interaction between home and service providers as children become adults.

What has Mark learnt? He believes with hindsight, it is important to set the foundations when children are young and have high expectations for your child. He wishes he knew 15 years ago what he knows now and maybe as a parent he would have done some things differently.

It saddens him that many faces involved at committee level have been around for a while (his wife included) and new members seem reluctant to become involved at the "bigger picture level". But on a positive note Mark feels he made some lasting friendships from being involved at committee level; friendships with others who face the same hurdles every day. ☺

Rose Clark

1996 - 2001

In 1992, Rose's small son had been given a label of Pervasive Developmental Disorder with autistic features! Rose discovered through visiting an Occupational Therapist in Hobart after travelling from their home in Wynyard, there were others interested in this thing called autism and attended the first get together in Launceston to form Autism Tasmania. Rose recalls thinking that her son couldn't be autistic as it was too rare.

Her recollection of the early nineties is that not a lot of people had heard of autism as opposed to the recognition Autism Spectrum Disorder (ASD) receives today. Rose says that "Autism Tasmania was really ahead of its time, by having on its original letterhead 'supporting people with autism and related disorders' and acknowledging that autism was perhaps much wider than those being diagnosed."

Fifteen years on Rose feels the general public is now aware of autism or ASD. While she believes Autism Tasmania was instrumental in lifting the profile within Tasmania, the media has also played a part. "Television shows such as A Country Practice began to feature autism." However she is disappointed with professional understanding on many levels. "We still do not have good diagnostic skills in the state." Parents regularly complain to Rose in her role as Family Support Coordinator, that it can be a long and difficult process to get a comprehensive diagnosis which it was fifteen years ago. "A clinical psychologist from Victoria regularly visits Launceston and works out of a local paediatrician's rooms, but there is a waiting list to see her and it can be expensive. This is not good enough."

Rose also sees that it is often very difficult for adults to get a diagnosis, particularly those with Asperger syndrome who grew up when Asperger's was not recognised. "As Asperger's is now recognised by Centrelink - and this has been a huge shift - diagnosis is important. The prevalence rate has gone from 1 in 1000 (from overseas data) to 1 in 160 (from an Australian

study) in the last 15 years yet diagnostic skills in Tasmania remain an issue."

However Rose has seen many positive changes which began with the establishment of Giant Steps in 1995 which really brought education and autism spectrum to the fore. The majority of changes and development in autism in the state have been brought about through the action of parents. These include the Giant Steps centre, home ABA programs and the expansion of autism specific knowledge in other service areas.

These changes have been evident within the Education Department where she is employed part time as NW Autism Consultant. "Early Learning has become quite autism specific in its approach and pays heed to autism issues. They also provide information and considerable support to parents; parents often make contact with Autism Tasmania when their children move from Early Learning to Kindergarten and that support is no longer there."

The establishment of the Asperger support group in Hobart has been a highlight for Rose and she meets regularly with this group. "They are such an inspiration, they are so articulate and can tell it how it is."

Fifteen years on, lack of money, lack of appropriate services and lack of knowledge of the overall numbers of people with ASD in Tasmania are still major issues. Rose believes that we need to think beyond generic services for people on the spectrum. In her Autism Tasmania work Rose still sees a lack of understanding amongst some service providers about ASD and this comes back to the quantity and quality of training received. "The more you learn about ASD, the more there is to learn."

But Rose is heartened that there are some wonderful people doing some wonderful things. After a long involvement, she remains committed to the autism community and always felt she was the person for a cause. She just didn't know what that cause was until her son came into her life. ☺

Tips for Surviving the Holidays

1. PLAN your holiday time
2. Discuss with your child's teacher any things of interest that have happened in the classroom that can be carried over to the holidays
3. Make a list of your child's likes and dislikes, e.g.: activities such as bowling, swimming, etc and things that you know that will have an impact as a reward
4. Schedule things your child likes doing straight after those that he or she doesn't like doing
5. Use praise when tasks have been completed or behaviour has been appropriate, no matter how small it may seem
6. Teach one new little leisure skill during the holidays
7. Set up routines and keep to them. Design visual schedules and timetables that are visible to your child and that they can constantly refer to if necessary
8. Warn of changes in routine ahead of time and try to replace the change with a highly preferred activity
9. Give yourself a break: plan some family activities which include your other children. Organise holiday respite if available.
10. Set up support networks wherever possible (extended family, other parents, spouse, older children, respite, kind neighbour etc.). Someone maybe happy to take your child for a couple of hours so you can go shopping by yourself or take your other children to a movie.
11. Plan in advance your responses to possible negative behaviour reactions, write yourself a list: *what to do if..... what to say when.....*
12. Contact your local council to find out about any integrated holiday programs that maybe offered in your area
13. Give siblings a break too. Enrol them in their own holiday activities or camps. Treat is as acknowledgement of their patience and understanding through the year.

Original article from Keynotes, December 1994 with additions and modifications by Rose Clark, 2007

Alison Burden Visit

With the generous support of Autism South Australia and through the remainder of our Tasmanian Community Fund grant, we recently brought their Family & Information Services Co-ordinator, Alison Burden to Tasmania for a two day visit.

Alison met our Committee and staff in Launceston to help us better understand the wider picture of how we might structure the information and support services we offer to members and the wider autism community.

Her experiences and advice has helped understand how we can manage a peer support program and make it complementary to existing autism interest groups. Autism SA run a single point of contact information service, so we gained an practical understanding of how large numbers of client contacts are handled, how different client needs are responded to and the information gathered at time of contact.

Alison gave us examples of the type of information that is provided to people who contact their Association and many practical suggestions of things we can do to improve services.

Inside the back page

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

Disability Services Review

Consultants KPMG have completed targeted interviews and regional stakeholder forums to discuss 'what's working well and what could be better' in the Tasmanian Disability Services system.

A summary of Forum outcomes will be posted on the DHHS website soon. Input from stakeholders can still be provided by emailing disabilityreview@kpmg.com.au or contacting KPMG team members:

Liz Forsyth — 0418 659 857

Sarah Gruner — 0402 134 534

The review will finish in March 2008. ☞

Apex Trust for Autism Grants

The Apex Foundation Trust for Autism Grants for 2008 were announced in November. Fifteen applications were received for \$15,000 available and seven high calibre submissions short-listed for consideration by the Autism Advisory Board's Professional Committee.

Two research grants were recommended:

\$8,000—Dr Mark Nielson, Lecturer, School of Psychology, University of Queensland for a project entitled "*Synchronic Imitation in children with ASD: Imitation and the Social Deficit Hypothesis*"

This project looks at one of the major differences observed in children with autism—that they do not imitate in the same way as children without autism. Imitation is central to a child's development —when doing what others do, children learn about how the world works. Dr Nielson wishes to examine synchronic imitation or 'mutual copying' at its simplest level—copying of repetitive actions. Other research area has typically focused on assessing imitation of activities designed to

develop new skills, which is a more sophisticated form of imitation of copying.

\$7,000—Dr Jill Ashburner, Research & Development Officer, Autism Queensland for a project entitled "*The introduction of keyboarding to students with autism spectrum disorder: a help or a hindrance?*"

Many students on the autism spectrum find handwriting difficult, putting them at a significant learning disadvantage. Little work has been done to evaluate whether the use of portable word processors leads to improved competency in written communication for these students. ☞

Autism Victoria changes

After 16 years as their first full-time Executive Officer, Amanda Golding left Autism Victoria in mid-October. She is a well-known and highly respected member of the autism community in her home state, nationally and internationally.

Amanda leaves a lasting legacy in the huge advances in the development of Autism Victoria. Her most recent achievements include securing funding for the establishment of the Autism Research Centre, a joint initiative of Autism Victoria and La Trobe University; and the current partnership with the Victorian Government to develop the Autism State Plan.

Both personally and through Autism Victoria, Amanda has helped Autism Tasmania enormously over the life of our Association and we thank her and wish her the very best as she starts a new part of her life in her own business.

Alison Byrne is the new CEO of Autism Victoria and brings a different mix of skills, having been the Executive Manager of HeartKids Victoria and Communications & Relationships Manager for the Children's Heart Research Centre at the Royal Children's Hospital. We wish her well in the new role and look forward to continuing a good relationship with Autism Victoria. ☞



*Information & Support
Training & Consultancy*

*General Enquiries
& Library*

Contact ~ Rose Clark

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Regional Autism Interest 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 Call Carolyn Moore - 6458 2096
Brighton Autism Mother's Group	Brighton Primary School 27 Downie Street, Brighton	Every 2 nd Wed morning 9 – 11am Call Keitha Duncombe—6268 0698
Cressy/Longford	Cressy District High School Main Street, Cressy	Last Friday each month 3.30 – 4.30pm Call Natalie Hill – 6397 6327
George Town	Wattle Building Agnes Street, George Town	Last Wed each month 7 – 9pm Contact Rose Clark
Lilydale/Exeter	Alternates between the areas	Last Friday each month 10.30 – 12pm Contact Rose Clark
Hobart	Tascare 231 Main Road, Moonah	2 nd Thurs each month 7.30 – 9.30pm Contact Rose Clark
Asperger Syndrome Support Group [Hobart]	Tascare 231 Main Road, Moonah	Last Sunday each month 2 – 4pm Contact Rose Clark

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