



From the President

I begin the new year with an apology as this issue should have been out before Christmas. However, another three issues of the newsletter will be produced in 2005 and I hope the articles included make interesting reading.

The start of a new year is often a time of new beginnings and I know many young families will begin the school year with mixed feelings. Has enough planning and transition work been done for the person with an autism spectrum disorder to change classes, teachers or schools? Are there adequate education, respite, supported accommodation and work options available to our 18 year olds and above, who are no longer eligible for the services provided as children? My now adult son is about to embark on year 13, fulltime in a mainstream college, after having spent the last eleven years in a mixture of special and regular education. We face this change with some trepidation. Has enough been done enough to ensure a smooth transition? How will he cope with this change and leaving the security that Giant Steps and an autism specific environment have offered him? Whatever one's circumstances, it seems that planning and communication, with schools, teachers or involved agencies, is essential although not always easy.

An exciting year is ahead of Autism Tasmania. In 2004 our main focus as an organisation was to secure ongoing funding for the Family Support Service, primarily to fund the Family Support Coordinator position. I am pleased to

report that we have been successful in obtaining several grants totalling approximately \$30,000!!!! This is the result of a great deal of work being done by the committee and information on these grants and how the money will be spent is included in this newsletter. While we were delighted to receive these grants, they are all "one-off", and we have forwarded a submission to the Minister for Health and Human Services for consideration in this years budget.

Our first key event this year is our

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second State Autism Conference to be held at the University of Tasmania in Hobart on Saturday 9th April. Mark this date in your diaries now, as the keynote speaker is Dr Tony Attwood, who will be presenting several papers with his co-presenter. Tony Attwood is an excellent speaker who first visited

Tasmania in 1993. In addition there will be two sessions of concurrent presentations from local presenters. Look out for conference registration information which will be out in the near future.

Ros Ward President

Blame it on testosterone

Spurred by the mystery of autism, a disorder afflicting his four-year-old son, David Cohen meets a leading specialist

Reprinted from *The Australian* Wed. 12th January 2005

What happened to my son? It would be so much easier if the answer were clearer. Eliot, who is four, has autism, which is a wild card. In Australia, the estimated 80,000 families affected by the same condition are probably wondering much the same.

Autism, which was first de-scribed In 1943 by Leo Kanner, a child psychiatrist at the Johns Hopkins University, but which has surged into the public consciousness only during the past decade, is a mysterious spectrum of neurological disorders. Among the behaviours most linked to it are poor or non-existent language and social skills, and a propensity for repetitive, frequently obsessive behaviour, including hand-flapping, toe-walking and self-injury.

The word is derived from the Greek *autos*, meaning 'self', which is what Kanner saw in his controlled studies of children possessed "with an alone-ness from the beginning of life".

In Kanner's time, the condition was thought to occur in perhaps one in every 10,000 children; a decade ago that number had jumped fourfold; today, the figure could be as high as one in 250.

"When I go to a dinner party these days I do find more and more people who know something about autism, which simply wasn't the case 10, even five years ago," says Amanda Richdale, a senior lecturer at RMIT's School of Health Sciences, who specialises in the

disorder.

Researchers such as Richdale attribute today's figure partly to improved screening, greater public awareness and a wider understanding of the condition among clinicians. But a fuller explanation for the condition remains almost as elusive as the possibility of ever finding a cure — all the more so, they believe, in Australia and New Zealand, where public spending on its related scholarship is regarded as negligible.

Frustrated by the lack of available local information, as well as having a professional curiosity to meet one of the world's top newsmakers in the field of autism research, I recently visited Cambridge University to meet Simon Baron-Cohen, one of Britain's most respected autism researchers of the past 20 years. This past year, the Oxford-educated Baron-Cohen's words struck a chord outside Britain, attracting scholarly attention where resistance was expected, and where some still remains, in Australia and the US.

What he has to say is "extremely significant and very powerful, though I wouldn't say I agree with every thing he puts forward says Monash University's Lawrie Bartak; one of Australia's most experienced researchers in the field and the president of Autism Victoria.

Baron-Cohen's theories about empathy, in particular,

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are generating a buzz among scholars such as Bartak, professor of developmental psychopathology.

Baron-Cohen believes a key reason Eliot has this condition might be because he is a boy. Or, as his new book puts it, because he has an “extreme male” brain. The book, *The Essential Difference: The Truth About the Male and Female Brain* (Perseus Publishing) lays out the case. The work suggests that the capacity for empathy is the critical cognitive difference between men and women. And it speculates that this empathy gap between the sexes could provide a key for understanding autism.

The Cambridge scholar identifies empathy as “the drive to identify another person’s emotions and thoughts, and to respond to them with an appropriate emotion”.

At the core of his thesis, he postulates that the natural wiring of the, human brain tends either towards capacity for empathy or towards or understanding systems.

Baron-Cohen labels them E-type and S-type brains. He shows me the little chart he uses to explain the scoring on the questionnaires given to subjects. One corner frame shades into deep the other into pink. “We find,” he explains, “that on average women tend to score in this light blue area, so their empathy is better than average. But their systematising is not as strong as their empathy”.

Moving a finger across the frame, he continues: “Now here. Men on average are in the pink range. They’re interested in how things work in systems, and less interested in talking about, say emotional problems

The final point of the demonstration, and the book’s clincher, is that autism represents nothing less (or more) than an “extreme version” of the male brain. As Baron-Cohen tells it’s almost like an exaggerated “guy thing”, a disorder in which autists tend to be more male than most men.

But he takes pains to distance his work from the “Mars and Venus” tradition. Imagining that men are from Mars and women are from Venus is not helpful scientifically, he writes, “and distracts us from the serious fact that both sexes have evolved on the same planet”. Not to mention any autistic offspring they may have.

Clinicians since Kanner have debated the degree of conventional intelligence possessed by children with my son’s condition. The usual assumption is that most exhibit some intellectual disability. One of the Implications of Baron-Cohen’s paradigm is that the opposite could be true, at least insofar as the “extreme” brain can be taken to mean one possessed of an extreme intelligence.

This is another of the areas where his findings dovetail with some of his previous work. He has argued that a number of great thinkers, male and female, may themselves have possessed such highly intelligent, extreme brain.

With mathematician, Ioan M. James of Oxford University, he recently made scientific headlines by arguing that at least three of the well known personality traits of Einstein and Newton – obsessive interests, difficulty in social relationships and profound communication problems – suggested that these men were autistic.

His latest findings in the psychological realm also fit with his continuing work on autism’s biological root. Another recent work, published this year looks at amniotic testosterone levels, which go to the heart or brain of his over-riding theory on the condition. Based on their study of thousands of samples of amniotic fluid, Baron Cohen and his colleagues at the autism centre have documented that children who experienced high prenatal testosterone levels make less eye contact as toddlers and have lower communication skills at age four, though he admits the evidence for any relationship between foetal testosterone and autism has yet to be established.

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If further research substantiates his hypothesis, he says, it would revolutionise the way in which autism is understood and initially diagnosed, possibly opening the door to far earlier intervention with intensive behavioural therapies.

But it would also “open up an ethical can of worms with regard to terminations of pregnancy as well. What would be lost, as well as gained, by that?” he asks.

For now, however, he has enough controversy on his plate. Writing in the online magazine Salon, one reviewer, Amy Reiter, slammed The Essential Difference for appearing “to reinforce the worst kind of gender stereo-types”. Overall, one couldn’t help but feel sorry for the scientist, she wrote, but “maybe that’s the empathiser in me”.

Yet many others feel differently. Whether one agrees with Baron-Cohen’s approach, sexual politics, or science, noted one reviewer in the British newspaper, The Guardian, his book’s argument is “a treat for those who simply enjoy a good idea”. And when the magazine Newsweek recently invited him to take part in an online discussion about his theory, the publication found itself flooded with hundreds of inquiries with readers across the world

Autism researchers such as Verity Bottroff, head of Flinder’s University dept of disability studies have tended to be responsive, too.

“Whatever the shortcomings of assigning gender labels of this type, anyone who’s working as a serious researcher in this field will be following this work,” says Bottroff

Her view is echoed by another high profile researcher, Geraldine Dawson, a professor of psychology and director is the biological basis for the of the University of Washington’s Autism Centre in Seattle, reminds me that US insurance companies pay out as much as \$US 250,000 (\$300,000) to the parents of children diagnosed with the condition.

Dawson, a pioneer in the early detection of autism, likens Baron-Cohen’s contribution to those that once helped clinicians understand heart disease. At one time, cardiologists interacted with patients only after the onset of problems, and doctors tended to focus on determining whether people had suffered heart attacks.

Only when researchers began looking at underlying areas such as blood pressure and cholesterol levels did they make significant progress in diagnosing and treating the disease, as well as preventing its occurrence.

What Baron-Cohen “is doing is to think about one way in which we can consider autism along a dimension and from his perspective, of course the dimension he attaches to it is one of genders says Dawson.

Researchers need to investigate whether that hypothesis is accurate, but the dimensional approach he is taking “is right on target”, she says.

But not every scholar in the field gives his ideas a complete thumbs-up. Even Bartak, while hailing Baron-Cohen’s explorations for their significance and perspective, cautions that some of the more headline-grabbing material is “interesting but a bit simple”.

“I mean, I don’t want to damn it and it certainly represents one way of looking at the subject but it seems to me that the causes of autism are a bit more complex than what he’s making them out to be here,” says Bartak.

While he agrees there is a tendency for males to process information in the way Baron-Cohen notes, he says normal males “also have imagination, whereas one of the problems with autism is a lack of imagination. So clearly there’s an additional factor going on here beyond the style of processing information.”

Another problem is girls. Autism affects more than four times as many males as females, and those girls who are autistic tend to process information in much the same

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way as their male counterparts.

Still, says Bartak, it doesn't explain why any girls at all should be affected.

Baron-Cohen's response is that girls are indeed exposed to low levels of testosterone in the womb. But they start from a lower base than boys, leading him to speculate that they may require a bigger dose of whatever it is that causes the hormone to be elevated.

For Bartak, however, that only raises as many questions as it answers. "It's possible, I suppose," he says, "but the genetic evidence suggests an abnormality of wiring

in the brain, so to speak. We know that's likely to be influenced by testosterone pre-birth, but there's no evidence for that yet. So it's conjectural at this point, really."

Baron-Cohen is pleased that his work is being considered at all. He seems genuinely relieved that more scholars appear to agree than disagree with Pinker's view of his work as being "neither politically correct nor politically oblivious".

All the same, he knows his latest idea is far from the mainstream "it could well be seen as eccentric" admits the Cambridge Professor.

Open letter to parents of an ASD child—by Mary Brake

Dear fellow Parents:

Recently I attended PD given by Vicki Bitsika. It was so helpful to me that I was thinking of you during the PD and wishing that you were all with me. I have decided that perhaps by sharing it with you, you too might benefit as I did. Whilst I could write 'I' and 'we', I have chosen to keep the summary of Vicki's address in third person, as she spoke it.

Vicki spoke at length concerning PARENTS.

She spoke of the journey most parents travel to reach

The point of diagnosis.

By this time she believes, parents are well accustomed to being disbelieved, blamed, ignored and dismissed. They are used to being told 'they will grow out of it', being termed an 'over sensitive parent' etc. Basically they have become used to being treated like idiots, who are a bit neurotic and don't know what they are talking about.

Finally, after much perseverance and fighting, they are given a Diagnosis.

Two reactions then occur simultaneously: relief and shock. The relief is about 'I am not neurotic, was not imagining.... Etc etc. The shock is about the realisation that their child will have problems for the rest of their life. This is the death of the perfect child. This is the loss of the opportunity to become the parent that they always imagined they would be. This is the death of so many dreams and plans. At this time life telescopes before the parents in a manner that most parents are oblivious of. Parents of children with autism realise that they have been the fighter –eg for the diagnosis, they are the advocate, the supporter etc and they realise that they can never die. At each stage of life, their child will need them. They now are trapped. In their mind's eye they see their child at kindy age, at college age, at young adult age, etc etc.. They are filled with intense emotions.

Most parents feel **ANGER** –intensely!

They are angry about the fights they've had to the point of diagnosis, they are angry about the delay in the diagnosis. They often generalise this anger, to include all professionals.

Most parents experience **DENIAL** –intensely!

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They may minimise the autism based symptoms and focus on splinter skills.

They may develop high (unreal!) expectations of the child -and the staff

They may frantically search for a cure –eg diet, vitamins etc.

Most parents experience **DESPAIR AND GUILT**

.they attribute their child's difficulties to an action of their own. This is often deep within, and sometimes not even acknowledged to themselves.

They experience acute feelings of hopelessness. The natural mothering instinct feels that it wants to nurture, fix, and make things right. They can't and so they may feel inadequate and helpless. This often results in periods of inability to function on a day to day basis. Vicki told of one of 'her mothers' attending a meeting in the winter. She had forgotten to put her shoes on. Along with this inability to function is an inability to connect with the outside world. They often feel in a capsule of their own family needs.

Most parents experience **SHAME**

They may avoid social interactions and sever friendships. develop selective hearing. A parent may be given five positive points about their child and *one* 'to be worked on'. They will hear *only* the negative. It will be as if they simply haven't heard the other points.

Parents will ask many questions about their self worth.

Most parents experience **ACCEPTANCE**

At this stage parents are able to view their child outside of the ASD label.

They accept adjustments in family life

They accept that their own feelings go in cycles. They develop a wider world view and focus on their own life as well as their child's life.

IMPORTANT!!!!

These stages are not mutually exclusive. Parents may experience a gambit of these emotions *simultaneously*.

They move in and out of these emotions *for the rest of their life*.

Stressors continuously impact on these emotions. Each new stage that the child reaches brings with it new grief, new anger, new helplessness, new shame, new despair. These parents live with chronic grief *all their life*. Vicki has conducted research in two states and has found that about half of the parents with children with autism feel 'stretched beyond their personal limits' about *half the time*.

I found this acknowledgement of the difficulty of the journey to be immensely helpful. It is the first time that I have received validation of the plethora of emotions that I have struggled with. As Vicki spoke I felt myself wanting to call out 'Yes, Yes!' I felt a little less 'crazy'! I have often felt embarrassed with myself at the spontaneous and intense emotional reaction that I often experience in the most mundane of circumstances. Since Vicki's address, I have decided to be more understanding of myself and less harsh on myself.

Mary Brake

POINTS TO PONDER

1. Risk more than others think is safe
2. Care more than others think is wise
3. Dream more than others think is practical
4. Expect more than others think is possible
5. And never, ever give up"

Something to think about?

Attributed to Simon Latchford

Proprietor of a successful yacht charter business

AUTISM TASMANIA INC.

presents

**Tasmanian State
Autism Conference 2005**
‘THE MANY FACES OF AUTISM’

with Keynote Speaker

Dr Tony Attwood

**Internationally recognised ASD authority,
and his colleague,**

Michelle Garnett

Date: Saturday April 9th, 2005

Venue: Stanley Burbury Centre, Tas. Uni, Hobart

Time : 9am—5pm

Cost: Registration form available soon.

Commonwealth Respite for Carers Funding will be available for people who care for a person with ASD.

Enquiries : Penny Cromarty ph 6334 1119 (h).

Autism Prevalence in Tasmania - by Mick Clark

Getting accurate or authoritative information on the number of people who have an Autism Spectrum Disorder in Australia can be a frustrating task. If available at all, information is often outdated or incomplete, studies use varying methodologies, their results are often conflicting and we're left with little understanding of the real picture. Yet accurate information from an authoritative source is the basis of any serious discussion of public policy-making or service provision design, whether locally, regionally, in health or education. We need the facts.

Autism Tasmania is involved in two responses to this problem. The first is the release of its Statement on Prevalence of Autism Spectrum Disorder (ASD) in School-Age Children in Tasmania – November 2004, tabled by representatives of Autism Tasmania, ABIT and ACD at recent Department of Education consultative groups discussing the restructuring of education services as a result of the Atelier Report – “Essential Learnings for All”.

The Statement is a simple attempt to put some logical, real numbers into the discussion on service changes, so that we can start to get a sense of how many people in Tasmania have their lives impacted upon by an ASD. It is derived from sound sources, to give an overview and fill a void, as there is no accurate information available from government service providers giving a complete picture. A detailed explanation of the Statement is provided latter in this article.

The second and more detailed response is through the Autism Council of Australia (ACA), which has gained Commonwealth FaCS funding for a research study into autism prevalence. The study will provide the best current evidence for estimating autism prevalence in Australia, provide a framework for interpreting & understanding conflicting findings of autism prevalence, review the nature and completeness of State & Territory data and make recommendations on autism data collection.

Dr John Wray from the Western Australian Child Development Centre will lead the project, with associate investigators, Dr Emma Glasson of the Telethon Institute for Child Health Research, University of WA and Dr Katrina Williams of Westmead Children's Hospital, Sydney. The project will commence in February 2005 with a final report due in February 2006.

Dr Christopher Gilberg, in his paper presented recently at the Biennial National Autism Conference in Canberra, reported that there have now been some 100 prevalence studies of ASD worldwide and only 4 or 5 incidence studies, generally based on registers which are unreliable. Of the 100 prevalence studies, 42 used excellent methodology and from these the prevalence of ASD is now generally regarded as 1% of the population of school age children.

As the ACA pointed out in its funding proposal to the Federal Government last year, Autism Spectrum Disorders can no longer be dismissed as “a low incidence disorder”. It is ten times more common than cystic fibrosis and muscular dystrophy combined; is more common than cerebral palsy (1.5 – 4 per 1,000); or Down syndrome (1 per 660 live births compared with ASD at 1 per 165); and more common than severe vision or hearing impairment.

Based on data collated by the Autism Council of Australia's (ACA) Professional Committee, chaired by Dr Verity Bottroff of Flinders University, the estimated prevalence of ASD has increased from 2 – 5 per 10,000 (first cited in the 1960s) to figures between 60 – 90 per 10,000 (see Ehlers & Gilberg, 1993; Wing, 1996; National Autistic Society, 1997). The increase in prevalence is acknowledged as largely due to changing definitions of ASD, as well as improving knowledge and diagnostic services (Patricia Howlin, 2004).

The Autism Tasmania Statement on Prevalence takes

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the current conservative prevalence rate of 65 per 10,000 (as used by the Autism Association of NSW) and applies it to Tasmanian population figures released by the Australian Bureau of Statistics (3235.6 Population by Age and Sex, Tasmania, 30 June 2000) and Tasmanian Department of Treasury & Finance (Tasmania's Population 2003). The following prevalence estimates emerge for the total population:

Age Group	Population	Mersey-Lyell	Northern	Southern	Tasmania
0 – 14 years	Total	23,000	28,300	48,701	100,002
	ASD	150	184	316	650
15 – 64 years	Total	71,192	87,598	150,740	309,530
	ASD	463	569	980	2,012
Over 65 years	Total	15,334	18,867	32,467	66,668
	ASD	99	123	211	433
All ages	Total	109,526	134,765	231,908	476,199
	ASD	712	876	1,507	3,095

Young People	Population	Mersey-Lyell	Northern	Southern	Tasmania
0– 19 years	Total	31,050	38,205	65,745	135,000
	ASD	202	248	427	877

School Age	Population	Mersey-Lyell	Northern	Southern	Tasmania
5– 19 years	Total	23,920	29,432	50,648	104,000
	ASD	155	191	329	676

Post-School	Population	Mersey-Lyell	Northern	Southern	Tasmania
15– 19 years	Total	8,165	10,047	17,288	35,500
	ASD	53	65	112	230

By applying the conservative prevalence rate of 65 per 10,000 and the generally acknowledged rate of 1% of school age children to the enrolled FTE student numbers from each of three main educational sectors, the range for the Tasmanian student population emerges:

	State (DoE)	Catholic Independent (CEO)	Non-Catholic Inde- pendent (AIST)	Total
Total Students	65,246	13,827	*7,968	87,041
As 65 in 10,000	424	90	52	566
As 1% of pop.	652	138	80	870

Association of Independent Schools Tasmania figures from 2002.

Simple as this is, we now have a picture of the broad numbers of people in Tasmania who have an ASD. The outcomes of the ACA prevalence study will provide more accurate and authoritative information that can only help discussions with policy-makers and service providers.

Autism Support and the Transformation of Schools

– recent discussions re: implementing the recommendations from the Atelier Report

The autism community has been reassured by the Education Department that it is committed to supporting children with special and/or additional learning needs and also to be accountable for measurable outcomes in their learning. Recently around the state, Parent Forums were held at which information on structure and support for 2005 were discussed. Parents were informed that the implementation process would not be sudden and that it would be reviewed throughout the process. An outstanding aim of the implementation is to *build capacity* of knowledge and practice for all Education Dept staff.

Essential Learnings (the ELs) is the name of the new curriculum that the Tasmanian Education Dept has adopted for state schools. All schools will be reporting on an increasing number of areas in the new curriculum starting from 2005.

Essential Learnings for All is the name of the report presented by *Atelier* after their *Review of Services for Students with Special &/or Additional Learning Needs*.

The commencement of implementation of the 16 recommendations from this report has seen the establishment of several *Project Oversight Groups (POGs)* on which there is representation from parent bodies, unions, administrative, teaching and leadership areas.

Recently a proposal was suggested for the structure of autism support. Three full time autism consultant positions were to be set up, one in each of the three new educational *Branches*.

Parents welcomed the increase in resources for children with autism, but outlined a strong concern for the loss of focus on the importance of early intervention. Parents suggested that the workload for such a position would run the risk of being less effective in meeting differing needs across the age groups and that the time required for supporting these was a tall

order. In times of crisis, attention would be unavoidably drawn to a single area with other groups 'missing out' or losing momentum.

Education Dept leaders reaffirmed the priority importance of early intervention and their commitment to support the transformation of schools. Further discussions were held about the proposal for autism support in the *Branches*, the outcome of which is below.

Positions to support Early Learning Centres in relation to children with Autism Spectrum Disorders

It is the intention to create three new 0.5 positions, early learning centre positions to support children with autism (one in each branch). These positions will be in addition to 3 Autism consultant positions (one in each branch), bringing the total number of positions provided to support students with autism to 4.5 full time (an increase from 2.0 state-wide in 2004 and 1.0 state-wide in 2003). The positions will be initially funded until the end of term 2, 2005, at which time they will be reviewed.

The Early Learning Autism support positions will provide:

- Support to and professional learning for staff working with children who have Autism Spectrum Disorders (ASD) in order to increase their capacity to provide effective early intervention to these children and their families;
- Transitional support to kindergarten teachers where children with ASD have been enrolled from an Early Learning Centre;
- Assistance and support to families of children with ASD as part of the team of staff employed at Early Learning Centres; and
- Continued support and advice to ensure the successful continuation of the *First Links* program.

ABIT – “Catching Up” Autism Behavioural Intervention Tas Inc—Supporting Families Teaching ABA.

Hello to Bulletin Readers,

As a new year begins and we resume with routine, our circles of influence continue to build. We can all be advocates for the needs of people with autism and Asperger's. In the most unexpected places people will seek you out if you are happy to share. Even the smallest experience can raise awareness.

If you haven't already begun, build your own 'circle of support' this year. One family's needs are as individual as the next so the more resources you have tailored to assist the better.

On the subject of advocacy, ABIT invites all interested parents and grandparents to a session on advocacy with Mr Bob Buckley, A4 Convenor. A4 is Autism Asperger's Advocacy Australia, a national organization. See the calendar below for details. There will be no charge for this session and all are welcome.

GUEST SPEAKER

Bob Buckley is Convenor of Autism Asperger's Advocacy Australia (A4), the national advocacy body formed to lobby on autism-specific issues at Federal Government level. A4 was launched at the 2002 Inaugural World Congress in Melbourne by a group of people aiming to address national challenges for the ASD community.

Bob has a 13 year old son with autism. He comes with both a practical and an academic background. Currently, Bob is a Visiting Fellow at the Australian National University in the John Curtin School of Medicine. He spoke about Australian data on autism prevalence and incidence at the Biennial National Autism Conference in 2004. Bob has worked with autism organisations at local, state and federal levels.

His presentation discusses advocacy; that is practical and effective advocacy for individuals with ASD, suggestions on how to identify what services are

needed and possible approaches to overcoming barriers people face in getting services. Bob's practical examples come from his experiences in advocacy both as a parent and as a friend of families facing major challenges. These experiences range from working with individuals with ASD functioning at relatively high levels to those with the most challenging support needs. His presentation will provide opportunity for people to ask questions about getting treatment, services and support.

For further information on A4 please access the A4 website at

www.a4.org.au

Best Wishes
Rush – President ABIT
rushm@netspace.net.au

Rosemary
Ph 6229 5760

For further information on anything in this article, please contact Rosemary.

Let's Get Together ABIT Calendar of Events 2005

Sat 26th Feb – “Advocacy” with Mr Bob Buckley, A4 Convenor. 7 – 9pm. Call to confirm Hobart venue. Ph 6229 5760

Your Committee at Work....

Grant Success

Over recent months, Autism Tasmania has systematically gone about seeking grants from philanthropic bodies and government to develop its services to members and the wider autism community. We're delighted to report three recent successes through the generosity of Tasmanian grant-making bodies!

\$4,000 from the Tasmanian Community Foundation through the Phillip Smith Education Fund, for upgrading the library as well as purchasing a laptop and digital camera for the Family Support Service.

\$1,500 from the Launceston Mayor's Ball to further develop the Family Support Service in the greater Launceston area.

\$17,560 from the Tasmanian Community Fund for our "Families Supporting Families" project, to further develop and implement a peer support network for parents of children with autism, in several centres in Tasmania and increase the capacity of individuals, parents and families to support each other.

Each of these grants will help us develop our overall "Families Supporting Families" project, through which we aim to build a sustainable family support network among existing support groups and create a model that can be replicated in subsequent groups that emerge. We want to give the autism community, especially families, a greater capacity for effective mutual support through increased skills and knowledge; help people work together for their common benefit; and reduce dependency on the Family Support Coordinator, so that we can use our scarce resources more effectively to reach and help more people.

Together with money raised through our sponsorship relationship with National Foods, these grants have helped secure the Family Support Service for 2005. The Committee is confident that with the wonderful support that is coming through from support groups

and members, as well as the activities planned for next year, Autism Tasmania is moving in the right direction.

Research Grants Announced Shortly

The Apex Foundation & Autism Council of Australia (ACA) will shortly be announcing the recipients of research grants for 2005. While the ACA & Apex Foundation have been working together for 30 years, this round of grant-making will involve additional funds from the ACA as the result of a \$20,000 donation for autism research by Gaffney International, the Australian distributors of Thomas & Friends merchandise. The ACA recently decided to use some of this money over the next two years to augment Apex Foundation Trust for Autism funds.

ACA Forum Outcomes

The Autism Council of Australia (ACA) held its first public forum in October, coinciding with the Biennial Australian Autism Conference in Canberra. Bolstered by a strong Tasmanian contingent, over 80 people participated in the frank and entertaining discussions. The key points made were:

Make Autism Awareness Week a truly national event – find an overall theme or slogan that States/Territories and groups can support within their existing programs.

Change the "sad-looking child" logo used around the country & present a positive image of autism.

Become a strong national voice for autism, start influencing policy at the national level, talking with Federal Government.

Develop an up-to-date website so people can get authoritative information on autism matters.

Police care, legal rights, differing education & accommodation approaches & standards across States & Territories were identified as matters requiring attention.

Tas. Disability Unmet Needs Campaign – DUNC. A newly formed Statewide Lobby Group comments by Rosemary Rush

In August 2004 a meeting of interested parties was held at Glenorchy Library. Representation came from most areas involved in supporting people with disability. These included carers, support groups, advocacy, day option and employment agencies. The members of Autism Tasmania were represented by Debra Manser and Rosemary Rush.

MAJOR ISSUES:

The issues that were constantly raised as significant, across the State were:

- Supported Accommodation (for individuals across the spectrum)
- Respite
- Day Options
- Lack of flexibility in funding structures/transfer of services.
- Lack of Forward planning

Several other significant issues were discussed for e.g. human rights, inequity in – education and training particularly Post-School options, abuse, rural issues, services for the ageing etc.. It became clear that the priority focus for the group needed to be on the provision of services for individuals no longer in the schooling system.

One of the solutions that rose from this first discussion was to encourage people to register with Disability Services. It was also realized that *we should not be precious about our own area, but work together to be a stronger and more credible voice.*

A Steering Committee has been established. Contact Mary Langdon at Tascare for more information or representation on the Committee of DUNC. Ph 6272 8265.

Northern Support Group lunch with Sue Napier

On December 6th at the Country Club Casino, MHR Sue Napier was a welcome guest of the Northern Support Group. Approximately 8 Autism Tas. members took the opportunity to enjoy a pleasant meal and to talk with Sue about some of their concerns and the issues affecting their children.

Sue was excellent company and was an attentive and



L-R Kerry Anne Buckby Jones, Rose Clark, (obscured) Julie Hatters, Margaret Pearce, Christina Booth, Bruce Pearce, Anna Strochnetter and Penny Cromarty.



Anna Strochnetter, Sue Napier MHA and Rose Clark at the Country Club Casino

Letters to the Editor

Dear Editor,

I am a compulsive reader of books about autism. I used to borrow quite a few when part of the AT library was housed at a member's home in Hobart. I was wondering if AT could possibly publish a complete booklist of the contents of the AT, library so southern readers like myself can be fully informed of options for borrowing?

Please keep up the great work with cutting edge articles and info

With thanks in advance,

Lisa Minchin

Thanks Lisa. The Committee certainly intends to distribute our book list to all members as soon as possible. Currently we are investigating software issues involved in centrally managing all of our library loans. If there is any member who can advise us in this, please contact Ros.

Editor, Cheryl

Dear Editor

In my travels around parent groups there has been a renewed interest in gluten free foods. Some families are keen to try this idea to see if it has any impact. What I'd like to do is to ask families for any products and/or any businesses that sell gluten free produce as part of their everyday business. For example my butcher, the Forth Butchery produces gluten free sausages - all the sausages sold there are in fact gluten free. The 'All Things Nice' bakery in Devonport makes a variety of gluten free bread and rolls to order. If anyone has any information that we can include in a list for parents they can email me on: micknrose@tsn.cc or phone on 64 232288 or 0407 320 048.

Rose Clark (Family Support Coordinator)

Dear Cheryl,

I am a member of the East Coast Autism Support Group and want to share this exciting news with other Tasmanian Support Groups. On Australia Day we were one of six nominees, and to our delight, we

were the overall winner of the Break O'Day Health Initiative Award 2005 for our "UNLOCKING THE DOORS" East Coast Conference on Autism Spectrum Disorder.

Over the past 3 years we have held a head shaving fundraiser, soup and sandwich Awareness and Information Day, several raffles and an Autism Awareness Fun Day and have raised over \$3,500.00. Pictured is the Australia Day Award, the flowers which were presented to us and a Cheque for \$250.00.



In association with Autism Tasmania and the Healthy Community Project, we presented a very successful Autism Spectrum Disorder Conference on the East Coast in November 2004. Registrations and interest were received from all over the State. We were very privileged to have Wendy Lawson as our guest speaker. MHA, Tanya Rattray, opened the conference for us and presented us with a cheque for \$1000.00 from the Premier. to help us continue our work over the next 12 months. She praised Autism Tas., the Healthy Community Project and East Coast Autism Support Group for our raising of awareness and support.

There may only be 5 parents in our group but with the help of our generous community and our friends, together with the invaluable assistance from Rose and Fiona, we have achieved this wonderful result. The wheels have already started turning for our next fundraiser and we hope to hold another conference early next year.

Karen Rawnsley

What a fantastic good news story! Ed

An Audience with Autism—September 30, 2004. Canberra

September 30, 2004 Autism and Asperger Advocates (A4) placed 650 white chairs on the lawns in front of Parliament House. Shown is a picture of the chairs just after we set up all the chairs and pictures, before our small crowd walked up Federation Mall from Old Parliament House. We had a “short and punchy” ceremony with politicians; then everyone “met” the Audience with Autism.

The media was well represented, though not as well as we would have liked. Ironically, the best coverage of the event was on radio where the visual image is not possible. Radio stations across the country interviewed Judy Brewer Fischer and Bob Buckley (whose last interview was after 10.30pm EST time for 6PR in WA). We got some television and print media coverage and we are still trying to track it all down.

We have a lot of follow up work to do with politicians; both those who attended and over 40 state and federal politicians, who sponsored chairs on their own behalf. We have some follow up to do with the media.



Members of the autism/ASD, including Asperger's, community sponsored over 600 chairs. This is a fantastic effort when A4 has a membership of 750. The level of participation made a significant impression on the politicians present. So congratulations to everyone who sent in their templates and money.

The team which put this together was magnificent. They organised the chairs, the templates & photos, the information for politicians and the press. We owe them a huge vote of thanks

Bob Buckley - A4 Convenor

Rally for Respite /Action for Accommodation

On the 17th November, 2004 a rally was held outside Parliament House in Hobart. The rally for respite and accommodation was initiated and organized by a parent group called D.R.I.E.A.M. in the north of the state because they can no longer accept the lack of respite/ supported accommodation in their region.

On the day questions were asked in parliament by Mr Morris and Sue Napier, Shadow Minister for Health on the issue that addressed all regions of the state. Ms Putt also addressed the matter and others drew attention to the lack of planning in disability services. Mr Morris presented a petition to the House signed by approximately 250 citizens of Tasmania praying that the House take note of the shortage of emergency respite

accommodation in the north of the State for people with disabilities.

The Minister for Health was unable to attend the rally. The spokesperson from D.R.I.E.A.M and Mr McKim and Sue Napier addressed the Rally. Several parents and other individuals also made personal contributions which added strength and insight to the message being conveyed to the Minister.

There was a good crowd present on the day with representation from families and their children and service providers.

Statewide there are still critical shortages in respite and accommodation.



**THE BULLETIN OF
AUTISM TASMANIA
INC.**

Postal Address: PO Box 1552
Launceston, Tasmania 7250

www.autismtas.org.au

*Providing lifelong support to
people with Autism and related
disorders.*

Family Support

Contact the
Autism Tasmania
Family Support
Coordinator,
Rose Clark
on
6423 2288 or
0407 320 048
or
autism@autismtas.org.au

Jottings

Advance Notice

Next Biennial Australian Autism Conference is in Brisbane in May 2006, hosted by Autism Queensland and the ACA.

Computer Assistance required

Do you have a working knowledge of CUTE file transfer? Our webmaster Geraldine would like to talk to you on a technical matter to assist with the smooth running of the website. If you can help, please contact her on gprobs@yahoo.com.au

Committee Meetings via Video Teleconference

As well as our three usual sites at the Royal Hobart Hospital, Launceston General Hospital and NW Regional Hospital (Burnie), we now have access to 7 other sites: Queenstown, Campbelltown, St Mary's, St Helen's, Flinder's Island, King Island and Smithton. If you would like to attend a Committee meeting and can reach one of these sites, please contact the Secretary so that a site can be booked and an orientation visit arranged beforehand.

We have our committee meetings on the first Wednesday of each month between 7.15 and 9.00pm and visitors are always welcome.



Some of the people who attended the Autism Tasmania picnic held at the Tolosa St Dam at on Sat 4th December