

26 OCT 1998



AUTISM NEWS

Newsletter of Autism Tasmania Inc.

Postal Address

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Australia

Edition 24
October 1998

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Autism Tasmania Committee

Autism Tasmania Committee			Committee Members	
President	Rose Clark	6423 1056	Lisa Minchin	6223 2317
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	Kathy Gill	62337175	Cheryl Scott	6344 8015
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Treasurer	Rosanne Lay	62442540	Sue Thorogood	6362 6298

From the President

As you will see from the committee member list we have some new names. Autism Tasmania Inc. recently had its A.G.M. in Launceston and we welcome some new members and say farewell to two retiring members. A summary of the A.G.M. is included in this newsletter and you will also find an insert containing the 6th Annual Report and minutes of the previous A.G.M.

Shortly after our A.G.M. two committee members attended the National A.G.M. in Tanunda, South Australia: A busy two days ensued with many interesting items on the agenda (see the report also in this issue).

Autism Tasmania has had many phone calls from parents of newly diagnosed children from around the state. Informal meetings are being held in the north and north west to share information, support and ideas. Since our last newsletter, two Asperger Syndrome Support Groups have been formed in the north and north west also inviting parents to get together to share information and listen to guest speakers. It is wonderful to see these new groups forming - meeting times, locations and contact people can be found in this newsletter.

The committee is in the process of finalising the keynote speakers and logo for next year's National Biennial Conference in Hobart. You will find out soon!

The committee looks forward to another year with the opportunity to work together with other interest groups within the autism community to provide a well planned year of activities.

Rose Clark

From the Editor

Welcome to another edition of *Autism News*!

This issue has tried to reflect the many and varied needs of our growing membership, comprised as it is of families with children across the age and severity range, professionals from a variety of fields and a host of other community members. As a result, it contains a number of different articles covering such topics as alternative interventions, recent research, communication strategies, autism web sites, Asperger Syndrome in adults, the Autism Register and an inclusion success story.

In addition to our regular articles is information about the recent Autism Tasmania Annual General Meeting, that of the national body, and an insert about our latest fundraising and community awareness project - "Be Autism Aware" lapel pins.

Remember, *Autism News* is your newsletter and feedback, contributions and ideas from the membership are always appreciated. The Committee is also in need of volunteers to help with newsletter production so please make contact if you are able to lend a hand. Many thanks to Cheryl Scott for her help with publishing this issue and to the many others named who contributed articles and information.

I trust that everyone will find something of interest in this edition.

Rachel Evans

PS. Please note, if you haven't renewed your membership yet, this newsletter will be your last!

Autism Tasmania Inc. - Annual General Meeting

Our Annual General Meeting was held in Launceston on 15th August.

Annual General Meetings do not historically attract a large number of people but are an important part of the democratic process in electing a new committee.

Twenty people attended the meeting and were privileged to hear a very informative address by Kathy Gill on her role as the State Autism Consultant within the Education Department. Kathy's talk drew a very good response with a lengthy question/comment time. In this issue is an article written by Kathy as a follow up to that talk.

The new committee were elected and we say a warm welcome to Jenny Carriere, Cheryl Scott and Sue Thorogood - an introduction to these newest committee members follows this article.

Farewell goes to both Jenny Vince and Liz Maddern who leave the committee due to growing work commitments. Our thanks goes to both of them for their time and effort.

We look forward to a busy year and its many challenges. Committee reports will be included in our quarterly newsletter.

Thank you to all those who made an effort to attend the Annual General Meeting.

It was a wonderful opportunity to catch up with you all.

Rose Clark

New Committee Members

Welcome to the following new members of the Autism Tasmania committee:

Cheryl Scott - Cheryl is a Speech Pathologist by profession and the mother of a 10 year old son with autism, currently attending Giant Steps. Cheryl, husband Vaughan, twin 10 year old sons and 6 year old daughter live in Launceston. Cheryl looks forward to a productive association with Autism Tasmania and hopes to be able to bring both her parental and professional experience to the committee.

Jennifer Carriere - Jennifer is from Hobart and is married with two children, Samuel aged 6 years and 5 year old Alexandra. Samuel has been diagnosed with Asperger Syndrome. Jennifer works as a senior relief worker at Oasis Community Centre in Hobart.

Sue Thorogood - Sue is originally from Adelaide and moved to Deloraine with husband Andy and sons Michael, 12 years, and Brett, 8 years, in January so that Brett, diagnosed with autism at 18 months, could attend Giant Steps. Daughter Cherie chose to remain in Adelaide to complete Year 11. Sue likes to keep busy and looks forward to active involvement with Autism Tasmania.

National Annual General Meeting

The Annual General Meeting of the National Association was again held in Tanunda, South Australia on the 4th and 5th September.

Each state sends two delegates to the meeting, usually their Executive Officer and President. This year Tasmania had two delegates, Kathy Gill and me.

The agenda for this get-together was very long and at times quite daunting. We worked both days until 7p.m. so that the agenda could be completed.

One of the major items on the agenda was a name change for the national body, up until now known as the National Autism Association. With impending incorporation the word 'association' had to be deleted, special permission (and payment) granted for it to be used. The majority of

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CORRECTION

Included in this newsletter is a copy of the 6th Annual Report and 97/98 Annual General Meeting, and minutes of the last A.G.M.

There is an error on the second last page of the report. The page is entitled "**Statement of Income and Expenditure**". In the Expenditure column there is an item listed as 'Secretarial Levy'. This should instead read 'Secretarial Levy', a levy paid to the National Association.

FEATURE ARTICLES

Men Not Really Behaving Badly

Is he selfish, cold, obtuse and obsessed with routines? If so, he could be suffering from Asperger Syndrome.

From the Sunday Telegraph, London, Robert Matthews explains:-

Barbara was still at school studying for 'A' levels when she first met Graham, already studying maths at university. "We dated for a year before getting engaged," she recalls. "Our courtship was fairly conventional, although on several occasions he dropped out of my life for a few weeks before re-appearing as if nothing had happened."

Those equipped with 20/20 hindsight would instantly see these absences as a warning, although of what is anyone's guess. Certainly in the early days of the marriage, Graham's behaviour simply seemed to conform to the typical male stereotype still prevalent in the early Seventies. "He just wanted everything to be done just as his mother had done it," says Barbara. "And he never helped keep the house tidy, or move anything that was not his."

But then other, more subtle and bizarre traits started to emerge: "Our weekly timetable became very structured. His life became run by the clock: 6.20 am alarm goes off, 6.22 get out of bed - that sort of thing. I noticed that every time I asked him something like "Would you like a cup of tea?" he would answer by saying "What time is it?"

Holidays fell prey to the same obsession with routine. "He liked to go to the same place for holidays. Places owned by the Landmark Trust ended up as a compromise as they all have a similar feel to them: the crockery is always the same design and the kitchen fittings are the same."

Barbara then found that Graham's eccentricities extended beyond home life. "He didn't make friends at work, and was often a figure of fun as he wore slippers in the office. Social events were a nightmare. He would do such things as mutter a lot and suddenly fall asleep in front of everyone."

Yet Barbara put up with it for more than twenty years. In the end, it was a reader's letter in a newspaper that unlocked the enigma of her husband. It described the symptoms of a condition that seemed to fit Graham

perfectly: Asperger Syndrome, a disorder first described by the Austrian psychiatrist Hans Asperger in 1944, and now thought to affect about one in 200, almost always male.

A consultant psychiatrist later confirmed Barbara's diagnosis. Her husband has all the classic symptoms of Asperger Disorder. Its most obvious manifestation is a love of routine and familiar surroundings. Then there are the all-absorbing hobbies that can seem utterly pointless: analysis of Derby winners, or a detailed knowledge of railway timetables. Those with Asperger Syndrome are also often clumsy and poorly co-ordinated.

Although irritating, such symptoms are hardly the stuff of wrecked relationships. What makes those with Asperger Syndrome so hard to live with is their profound difficulty in interpreting the thoughts and feelings of others. They may be perfectly intelligent and literate, but they have severe problems dealing with the constant "nonverbal" communication that passes between the rest of us.

The results can be bizarre; monologues that ramble on despite everyone hinting that it might be time to stop; a total lack of embarrassment about taking a nap in the middle of a dinner party; an astonishing inability to understand even simple jokes about human foibles.

But this lack of insight into other people's feelings can also be extremely corrosive. Those with Asperger Syndrome often seem cold, selfish and indifferent to the suffering of others. Such traits have led psychiatrists to draw parallels between Asperger Syndrome and autism: the condition characterised by extreme withdrawal, self-absorption and a craving for routine.

According to Dr Louise Wing, a consultant psychiatrist at the National Autistic Society, Asperger Syndrome is probably best viewed as a kind of watered down version of autism. Its subtlety can mean that many reach adulthood without a diagnosis.

"One of the problems is that there isn't a definitive diagnostic test for Asperger Syndrome", says Dr Wing. A feature it undoubtedly shares with autism is the lack of any clear cause. The current consensus is that upbringing plays no part in its development. Instead, it seems to be the result of some as yet unknown, and perhaps inherited, defect on the brain.

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Together with colleagues from some of Britain's top neurological research institutes, Dr Francesca Happé, a cognitive psychiatrist at the Institute of Psychiatry in London, has been using brain scanners to watch what goes on in the minds of those with Asperger Syndrome.

A group of patients were given short stories to read while they sat with their heads inside brain scanners. One such story tells of a burglar who is running from the scene of a crime when a policeman, who just happens to be passing, sees him drop a glove. Hearing the policeman's shout of "Hey you, stop!", the burglar turns around, sees the policeman, and gives himself up.

Our ability to "read" the minds of others enables us to see that the burglar thought he should surrender because he mistakenly thought the policeman knew all about the crime. Those with Asperger Syndrome fail to work this out, but they are not simply being dense, as Dr Happé and her colleagues have shown by performing the experiment again with stories about simple events. In one, a burglar accidentally treads on a mouse, which runs off, to be followed by the sound of an alarm going off. Asked why the alarm went off, those with Asperger Syndrome reached the same conclusion as normal people: the mouse triggered it. This is just plain common sense, and needs no insight into the minds of others.

The brain scanning revealed that when we need to work out what other people are thinking, mental activity is triggered in a specific part of the brain. Located in the medial prefrontal cortex, this area lies just behind and slightly to the left of the centre of the forehead. But in those with Asperger Syndrome, it remains dormant. Instead, an adjacent part of the brain, known as Brodmann's area, becomes active. This also seems to provide insight into the minds of others, but far less effectively.

Says Dr Happé, "Those with Asperger Syndrome can be intelligent and take a pretty good crack at such tasks, but they make tell-tale mistakes. For example, they may decide that a person is joking, when even a child would recognise that the person is lying." This lack among Asperger patients explains so much of what those in relationships with them find so hard to handle: the apparent "coldness", the mind-boggling obtuseness, the shocking insouciance.

Brenda Wall, whose former husband was diagnosed with Asperger Syndrome, is now trying to win greater recognition for the condition. "We just want doctors

and counsellors to be more aware that there might be something more fundamental causing these types of problems." She contrasts the lack of support and help in diagnosis of Asperger Syndrome in adults with the wide recognition of autism in children.

"To feel embarrassment", says Dr Happé, "you have to have perception of what's going on in other people's minds, and that is hard for those with Asperger Syndrome. It is vitally important to recognise that when they do these things, it is not just a case of 'men behaving badly'." Yet this is precisely the reaction of many GPs and marriage guidance counsellors when faced with the distraught partners of those with undiagnosed Asperger Syndrome. There is still little recognition of this disorder that is likely to account for a significant number of wrecked relationships. "The people who've got in contact with me are desperate for help, but there is very little available".

Dr Wing of the National Autistic Society says that although there is no prospect of a cure for Asperger Syndrome, some of its worst features can be managed by providing the regular lifestyle that those with the syndrome crave. "Having a diagnosis can make a difference, because it helps to stop people thinking that the person is just being awful, and relieves some of the guilt."

Dr Wing has a blunt message for those involved with someone with Asperger Syndrome: "You can either learn to cope with the symptoms or get out. But you are never going to be able to change them." Barbara agrees. She is filing for divorce.

Can a genius have Asperger Syndrome?

Christopher Gillberg, one of the finest clinical observers of autism spectrum disorder, feels that some people with Asperger Syndrome may be capable of creativity. Three quarters of Asperger individuals display special skills; they may have exceptional memories and display outstanding talents, often in music, mathematics or engineering.

These abilities and other characteristics – withdrawal, self absorption, love of routine, eccentricity, obsessive interests, difficulty in intuiting the thoughts and feelings of others, emotional coldness, inability to understand humour – suggests that a number of famous creative talents may have had the condition, mostly notably Ludwig Wittgenstein, Bela Bartok and Franz Kafka.

Many autistic people also like to think of Einstein as one of their own.

At Autism Tasmania's Annual General Meeting in August, many questions were asked of Kathy Gill, State Autism Consultant, about services for children with autism spectrum disorder and the role of the Category A Register. To follow up her presentation, Kathy has provided the following article to again address some common concerns.

Category A Register

The purpose of the following information is to clarify some of the issues that may be raised in relation to the Category A Register and the moderation process.

Eligibility for the Category A Register:

A moderation committee, which comprises four independent professionals with experience and expertise specific to the register being considered, determines eligibility. There are separate registers in the areas of Autism, Intellectual Disability, Physical Disability (incorporating severe health impairments), Psychiatric Disorder, Multiple Disability, Blind/Vision Impairment and Deaf/Hearing Impairment.

Decisions in relation to eligibility for the Category A Register are made according to strict, documented guidelines and it is the moderation committees' responsibility to ensure consistent application of the guidelines across the state to ensure equity. It is acknowledged that the moderation process is not easy and the committees work hard, considering each nomination conscientiously in order to fulfil their responsibility.

Eligibility for the Autism Register is determined on the basis of:

- A student's demonstrated functional abilities, particularly in relation to DSM IV criteria, and the associated educational implications and
- A confirmed diagnosis of Autism Spectrum Disorder from a professional or professionals with expertise in this area

Students with a diagnosis of Pervasive Developmental Disorder Not Otherwise Specified (P.D.D.N.O.S.) or Asperger Syndrome are not eligible for the Register.

A "high functioning" student with Autism would, by definition, not be eligible for the Register.

The Purpose of the Category A Register

The purpose of the Category A Register is to identify those students with the most severe level of disability in the areas noted previously. As disability falls along a continuum from mild to severe and profound it is recognised that there are students with an identified disability who will not be eligible for the Register. This is not to deny the existence of their disability or their additional educational needs. The Category A Register, however, is not meant to be a definitive list of students with a particular disability.

Access to special education resources is not dependent on eligibility for the Category A Register. The total special education budget is divided into central (Category A Register) and district (Category B Register) based budgets. The Category A Register is an administrative tool used to identify those students who will access central rather than district based resources. Placement on the Category A Register does not guarantee any particular level of funding. Students who are not on the Register are supported from district special education resources and have access to support from the District Support Service, including support teachers, speech and language pathologists, guidance officers and social workers.

Tasmania has seven educational districts and each district has slightly different funding models. Advice in relation to this can be sought from your District Support Service Manager.

Students with Autism who are not eligible for the Autism Register can still receive support and advice from their District Support Service and the State Autism Consultant. They may also receive funding from the District Support Service Special Education Committee. These services are provided in recognition of the range of support needs of all students with Autism Spectrum Disorders.

Documentation/Information Required:

The following documentation/information is required in order for the Committee to determine eligibility for the Autism Register:

- Guidance Officer/psychologist's report including: a social and developmental case history, a comprehensive cognitive or developmental assessment, including the assessment profile;

- Behavioural observation – Childhood Autism Rating Scale (CARS) completed by observation not report. This may be completed by a professional other than a guidance officer or psychologist;
- Educational report for all school age children outlining functional abilities and educational implications;
- Speech Pathology report; and
- Other documentation considered relevant to the nomination eg. Medical/paediatric, occupational therapy or parent report, etc.

Nominations for the Autism Register are forwarded through, and endorsed by, the appropriate District Support Service Manager. These nominations are then forwarded to the Committee. The results of the Committee's deliberations are returned via the District Support Service Manager.

Further information on the Category A Register can be obtained from the State Support Service or from the State Autism Consultant on 6233 7175

Kathy Gill

State Autism Consultant

HELP WANTED!

Do you value your quarterly newsletter?

Autism News plays an essential role in supporting and providing a voice for Autism Tasmania members, and educating the public about autism spectrum disorder.

The newsletter needs your help!
Are you willing to help in some way with compiling or publishing newsletter items? Please contact a Committee member and help keep the newsletter going!

Intervention Approaches

The following articles touch on some of the vast number of intervention options pursued in the management of autism spectrum disorders. If there are others you would like addressed in later newsletters, please let us know

The Benefits of Aromatherapy and the Calming Effect it Can Have on People With Autism

The following article (taken with permission from Autism News, Victoria, March, 1998) by Jane Harrison has been reproduced from *Communication, Winter 1998* (National Autistic Society, UK).

Aromatherapy is the safe use of the essential oils of plants in baths, massage and vaporisers. Certain oils are well known for their relaxing, balancing or invigorating properties and many can be used therapeutically to improve health.

There are many examples of how Aromatherapy has been used successfully with people with autism, both by qualified aromatherapists and by parents and staff who have had basic training. Aromatherapy is often used to help reduce anxiety, understand and address challenging behaviour, improve body awareness, promote sleep, improve a person's acceptance of touch, improve or develop communication and feelings of safety and trust in a relationship.

A combination of the relaxing effects of the oils and massage in a quiet, private room and the gentle responsive attention of the practitioner can often have profound effects. Someone who has been distressed may relax, their breathing deepen, repetitive movements may cease, their voice become gentle and eye contact become steadier.

Research has shown that the fragrance of essential oils used in such sessions will come to be associated, both emotionally and neurologically, with the resulting feelings of relaxation. So, for example, if lavender and sandalwood (both relaxing essential oils) are used regularly then, at times when the person is distressed,

the person will calm down more quickly. This effect has also been used to help people with epilepsy control the frequency of their fits.

The sense of touch can provide a clearer avenue by which people with autism can recognise and understand the people around them. Through massage, the practitioner can offer a quality of touch that is both calming and responsive to the needs of the person.

Sessions may be quite short at first, starting with areas of the body that are acceptable to the person. There are many examples of how people with autism have quickly developed an enjoyment of massage that surpasses initial expectations.

For more information contact Jane Harrison, Hands on Publishing and Training, 5 West Pathway, Harborne, Birmingham UK B12 9DU. Tel: 0121 426 3947.

References

Wan toler, S. and Dodd, G. (1988) *Perfumery: The Psychology and Biology of Fragrance*, Chapman and Hall, London.

Betts, T. (1994) *Sniffing the Breeze*, in *Aromatherapy Quarterly*, 40, pp 19-22.

Also on Aromatherapy

Aromatherapy and Massage for People with Learning Difficulties by H. Sanderson and J. Harrison with Shirley Price, Hands on Press, 1991.

Drug Therapy – Seizure drugs: not just for seizures?

The following article has been reproduced from Autism Research Review International, Volume 8, Number 2, 1994.

Anti-convulsant drugs may be a highly effective treatment for some autistic children with no overt signs of a seizure disorder, according to a report by Audrius Plioplys.

The physician cites case histories of three autistic patients, ranging in age from three to five, with no clinical suggestion of seizures. EEG tests on all three

showed abnormalities, and the children were started on the anti-convulsant drug valproic acid. All three showed dramatic improvement in language skills, imaginative play, and social interaction.

Before treatment, Plioplys says, all three children were diagnosed as autistic according to the Diagnostic and Statistical Manual III-R (DSM-III-R) which sets US standards for diagnosing psychiatric disorders. Following treatment, he notes, "although their autistic symptoms had not fully resolved, each one technically no longer qualified for the diagnosis of autism."

His results strongly suggest, Plioplys says, that researchers should study the effects of anti-convulsants on autistic children who do not have overt seizures, but who have epileptiform abnormalities on EEGs. He adds that testing should include both waking and sleeping EEGs.

The following article was published in the Herald Sun on 15 September, 1998:

Amazing Autism Find

By Helen Carter

The mother of an autistic boy may have stumbled on an incredible discovery in the search for a cure.

American Victoria Beck said a hormone drug given to her son Parker for stomach problems caused a dramatic change in his behaviour.

Within weeks he started to speak, respond and use the toilet - things he had never done before.

Experts have described his turnaround as near-miraculous.

"We noticed an amazing difference in eye contact," Mrs Beck said. "He became calmer and started sleeping all night long.

"We then realised he was no longer exhibiting the facial tics he had for two years.

"Three weeks after being given secretin, Parker began saying phrases such as 'I love you'."

Parker was given secretin, which stimulates the pancreas to produce enzymes to help digestion.

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About 120 autistic children have since been covertly prescribed the hormone, which does not have US Federal Drugs Agency approval.

Adults have also tried taking it, reportedly to great effect.

Results will be unveiled next month at a conference organised by the US Autism Research Institute, which is endorsing the treatment.

Director Dr Bernard Rimland said: "The discovery is possibly the most important development in the history of autism. Children who have received secretin have undergone dramatic improvements."

Autism Victoria executive director Amanda Golding said the development was interesting and could be a new direction in treatment.

"Many autistic children have digestive problems and with this, hormones are excreted which could lead to activity in the brain that causes autism," she said.

But she warned it could just be that improving stomach symptoms made the children feel better, which made them more communicative.

Music Therapy

Music therapy has established itself as a valid intervention over the last forty years and is currently practised in over fifty countries with varied client groups and across many different settings. While yet to be fully appreciated, the value of music therapy is well documented and recognised as being of great benefit to individuals of all ages presenting with emotional, cognitive, physical and sensory difficulties.

Various forms of music therapy have been found to be highly effective in assisting individuals with Autism Spectrum Disorder, many of whom present with an 'innate musicality' that remains intact despite often severe impairments in other areas. Research has highlighted the role of music therapy in facilitating and expanding :

- emotional expression/ understanding and benefiting emotional well being at different stages of life

- communicative behaviours and social interaction skills
- awareness of self, others and the environment resulting in increased spontaneous shared play
- attention, motivation and self confidence
- the ability to cope with change and variation
- fine and gross motor skills

Intervention has also been reported to decrease stereotypic behaviours by providing individuals with appropriate alternatives to obsessive, fixated behaviours.

According to Delton Hedges, Music Therapist at Giant Steps Tasmania: "Children with autism and other neuro-integrative or developmental disabilities are often isolated and cut off – not only by lack of speech but by the very way they perceive the world. Like Alice in Wonderland they may experience the world out of proportion, or as changing rapidly, without rhyme or reason. Music is an avenue, a pathway to their inner being. It is non-threatening; it is orderly; it connects with their minds, hearts and bodies. It is an invitation to a safe and wholesome party – an invitation to come, to join in, to delight and develop in harmony with the world'.

The music therapy approach is based on the premise that music is a powerful tool in reaching the inner being and expressing/influencing emotional states (as we have probably all experienced at some time), as a result offering a means to stimulate many other areas of learning and development.

Rachel Evans

Sources:

Brown, Sandra *Autism and music therapy – is change possible, and why music?* (complete reference unknown)

Trevarthen, C, Aitken, K, Papoudi, D and Robarts, J. (1996) *Children With Autism – Diagnosis and Interventions to Meet Their Needs*. London: Jessica Kingsley Publishers

Perspectives of an Inclusion Success

Michael Ward is 13 years old and attends Giant Steps two days per week and Larmenier School in Launceston for the rest of his week. The following articles are perceptions of Michael's inclusion :

From Trish Bourke, Special Education teacher at Larmenier...

I was on playground duty a couple of days ago and noticed Michael sitting amongst a group of friends. His arm was draped casually around Blake's shoulder and he was having a conversation with Amy. The conversation was a little one-sided but Michael was participating by answering questions put to him by the others. I thought back to April last year when Michael began his inclusion and I was struck by just how far he'd come in that short time.

When he arrived, Michael stuck out like a beacon in the playground, a solitary figure often taking a high position on the equipment or isolating himself from the other children. He was distinguishable because of his finger flicking, jumping and the little noises he made. His classmates were keen to include him in their activities but Michael mostly rejected their overtures, preferring his own company and creating his own order with his rituals. The kids persisted however and slowly, slowly Michael accepted their friendship.

I now have to actively look for Michael in the playground. He still has his solitary moments and the kids have learned to respect his need for time out and to leave him alone for a while. These moments are becoming fewer and Michael can usually be found in the middle of a group of kids going about the serious business of playing.

Having Michael at our school has had huge benefits, not only for him but for the staff and other children as well. It has given his classmates and teachers an opportunity to learn about autism firsthand. It has also enhanced their ability to accept and value differences.

His classmates revel in Michael's achievements, however small. They were thrilled when Michael graduated from velcro tab sneakers to lace ups because he had learned to tie his laces! They suggested a wading race so that Michael could participate in the school

swimming carnival, they supported his inclusion in the choir at the Launceston Competitions, they argued about who would run with him at the cross country carnival and they are looking forward to Michael going to camp with them. They have been extremely protective of Michael's differences when competing with other schools in the Friday sports roster and suggested that he, like them, have a turn at being captain of Minkey. High fives fly when Michael achieves something, however small!

There have been many memorable moments since Michael came to our school but I think the highest point came for me during the school cross country carnival. Michael and his running mate Amanda came into view minutes after the rest of the field in the final race of the day. The other children spontaneously rose to their feet to cheer Michael home. Michael knew! He ran the last few metres to the finish with a coy little smile on his face. He was met at the line by his mates, high fives flew, pats on the back were forthcoming, there were cries of "Good on you Michael!". Michael's fist shot into the air, "I won!". In fact we all won - this is inclusion at its best.

From Amy Quigley, Grade 6, Larmenier School...

When Michael first started at school he was sort of shy and kept to himself. When people wanted to play with him he would walk away. We would have to keep telling him it was time to play and to turn off his television (Michael used to repeat things over and over that he heard on TV. He doesn't do that as much now). Now he plays with us all day. He also talks to us more. We can ask him more questions like 'what do you have for breakfast?', 'have you been on a plane and where did you go?'. Also I showed him a picture of a ghost and he moved his hands and went "woah, woah" and then he said "boo!". When he did that I felt that he trusted us and could do something like that without getting embarrassed.

Michael knows all his friends' names and when we try to trick him by swapping names he goes along with it but he really knows who is who. He's starting to be able to take a joke and he's also learning the names of all the other kids who aren't really that involved. Also with Japanese he seems to listen well and take it in. If I say to him, "Konnichi wa" he will say it back and if I

ask him what it means he tells me it means hello.

Michael seems to have a great time at recess and lunch. We tickle each other and we pretend to go to sleep and Michael either says "Wake up!" or "Brrring". He's willing to play new games like hide and seek and he now will have a go and keep trying at hard things on the play equipment.

Sometimes when Michael does something to get really involved with you and looks like he's really enjoying himself I think I'm so glad he has come to out school and that he's learnt so much. Michael is really good at joining in things now and if Mrs Hogan asks something he sometimes likes to answer her or tell her something. Michael is also good at tuck shop. He uses good manners, asks for what he wants and does everything right.

If Michael accidentally scratches us or something, he is very sorry about it and he is very caring. If someone or sad or upset he will pat their back gently and say, "It's all right". Michael is very kind and he knows right from wrong. I get upset when Michael has to cover his ears and cuddle up to you when people in the class get too noisy and the teacher has to growl. I really like the way that children from other classes acknowledge Michael.

Do you have a success story you would like to share?
The newsletter committee would love to publish it!
Please send your contributions to:
Autism Tasmania,
PO Box 1552, Launceston, TAS 7250.

Early Special Education Services

Early Special Education Services (ESES) exists in regional centres of Tasmania as part of the State Support Service (Department of Education, Training, Community and Cultural Development), supporting young children with special needs and their families.

The goals of ESES are to :

- Provide children and their families with educational services which maximise development and independence, and facilitate access to services within the wider community
- Support the families of these children and promote their self sufficiency and self esteem by providing information, resources and services which will enable each child and family's needs to be met as effectively as possible
- Facilitate the transition from ESES to the child's next educational placement
- Utilise a transdisciplinary team model of service delivery to ensure maximum benefit for children and families

While specific elements of the program differ across regions, services offered may include :

- Home and Centre-based programs

- Parent and child sessions
- Toddler and pre-kindergarten groups
- Kindergarten support and support within local community programs
- Reverse integration groups
- Parent education and support programs
- Access to support services (including speech pathology, physiotherapy, occupational therapy, psychology, social work and itinerant specialist teachers)

For children with Autism Spectrum Disorder early intervention plays a crucial role in achieving maximum gains in early and later learning and in the development of communication, social interaction, self help, motor and play skills. It also provides opportunities for the growth of self esteem and confidence in a learning environment.

To find out about ESES in your region contact :

North : Jillian Buck (6344 1729)
f as above.

North West Suzanne Jones (6424 3111)
f 64234095-

North West/West Liz Maddern (6435 2021)
f 64350466.

South : Carolyn Rennie (6231 1625)
f 62314246

Thanks to Carolyn Rennie for providing information for this article

'How to Talk to an Autistic Child'

From the Autistic Children's Association of Queensland (Inc)

These recommendations are relevant for all language-impaired children but are especially crucial for children with an autism spectrum disorder. These guidelines pertain equally to speech (verbal input alone) and to sign language (verbal and gestural input).

- Adjust the complexity of language to the level of the child
 - (a) language structure (how you talk)
 - (b) language content (what you talk about)
- Avoid excessive talking – speak in clearly articulated utterances
- Gain the child's attention first before beginning to speak
 - (a) say his or her name
 - (b) use physical direction if necessary
 - (c) stop the child's current activity
- Talk about relevant topics
 - (a) what he or she is doing or attending to, if appropriate
 - (b) what he or she is about to do
 - (c) what he or she has just done
 - (d) events he or she is familiar with
- Use repetition, redundancy and paraphrasing
- Use "build-ups" and "break-downs" to help the child learn about language structure
 - (a) build-up : "shoe" – "shoe on" – "put shoe on"

(b) break-down : "take your spoon and eat the cereal" – "take spoon", "spoon" (point), "cereal", "eat cereal".

- If possible, relate utterances to objects, events, actions in the environment through gestures, touching and action demonstration
- Clearly segment your utterances by using stress, intonation and pauses
- Use gestures to accompany speech
- Let the child know that you are a willing listener by attending to his or her communicative attempts
- If the child is unable to communicate through speech or signs, encourage him or her to show you, and provide the words
- If the child's requests or demands cannot be fulfilled, respond simply and consistently – eg. "no drink now", etc.
- Use language to help the child anticipate future events, especially unexpected changes in routine
- Use language to review completed events, for example, by discussing an outing, etc.

Autism Tasmania Regional Contacts

North :	Sue Thorogood	6362 2698
North West :	Rose Clark	6423 1086
South :	Rosanne Lay	6244 2540

THANK YOU

Autism Tasmania wishes to thank the following organisations, in addition to those who included donations with their membership renewal, for their generous contributions:

Taroona CWA - \$25
Evandale Light Railway Society - \$185

News and Views

Giant Steps Update

The past few months at Giant Steps Tasmania have been hectic as always but also very rewarding and encouraging for all associated with the program. With all students arriving back at school for third term, we now face what has traditionally been our toughest time of the year financially with considerable optimism.

Recent months have seen huge changes in the way we see the program and a major component of this has been looking at ways to take the program beyond the boundaries of Deloraine to provide for many of the families and children who up until now have been unable to access our service. We would love to hear ideas and feedback from all members of the Autism community, so please don't hesitate to call or write to the centre if you have a view to express.

Enrolments are currently being sought for the 1999 school year and we encourage any interested families to contact us as soon as possible as the enrolment process can sometimes take a few weeks to organise.

Recently, almost a hundred family, staff and community members gathered to celebrate the creative talents of Giant Steps students at an Art Exhibition at Gallery 9, Deloraine. Almost fifty works were exhibited and some of the children also showed off their musical talents. The auction of art works that followed, made it a very successful fund-raiser for Giant Steps and it is hoped that this can become an annual event.

There are still several events left before the year is over including:

- Cocktail Party at the Abel Tasman Motor Inn, Launceston, 24th October
- Statewide finals of our Happiest Baby Quest, 6th-9th November
- Grand Final of the Happiest Baby Quest at Wrest Point Casino, Hobart, 5th November

Please contact Giant Steps on 6362 2522 for further information about any of these events.

Brett Hosking (*Brett is an Autism Tasmania representative on the Giant Steps Board of Directors*)

Young Autism Support Tasmania

(Supporting Families Teaching Applied Behavioural Analysis)

It's been a busy and energetic time for YAST and its members, as well as for me trying to find my way around being president. We have been making the most of our monthly meetings by dividing the evenings into time spent going through the agenda items, having speakers at our last two meetings, as well as giving everyone an opportunity to speak together as a whole group and in small groups. We've had lots of new faces at our meetings and that's always encouraging and wonderful to see. What is also encouraging is the positive feedback I've been receiving from those who've come to our meetings for the first time as well as our regulars.

We arranged another meeting from Jura Tender, the clinical psychologist from Perth who oversees our home based Applied Behavioural Analysis (A.B.A.) programs, in early September and once again that went very well. All families who made appointments to see Jura had reports of progress with their children. Thanks to the fundraising efforts of some of our members, especially Tracy Dillon and Peta Kelty, enough money was raised to pay for the expenses incurred during Jura's September visit. We will be bringing Jura back to Tasmania in November this year.

During the last few months we have been putting together a resource library with the help of money donated to YAST by The Variety Club of Tasmania. Our library consists of teaching aides for the purpose of ABA. One of our aims has been to set up such a library and I'm so pleased it is now up and running. These items are available to all families running a home based program and their therapists.

YAST meetings are held on the 3rd Wednesday of every month at Albeura Street Primary School in Hobart, at 7pm. Everyone is welcome whether you are a member or not. For those wishing to inquire about membership, our resource library or anything relating to our support group or ABA, please contact me on 6229 7818.

Grace Talbot (*President*)

News and Views

Asperger Syndrome Support Groups

In the North:

The first meeting of the Northern Asperger Syndrome Support Group was held on 22nd August. This was an informal get together of parents, friends and adults with Asperger Syndrome. Feedback was very positive and a second meeting was organised for 24th October to share information and participate in an open discussion on language development with Sue Brown, Speech Pathologist with the Child Development Unit. *For information about future meetings, contact Rachel Hodge on 6393 7183.*

In the North West

This newest Asperger Syndrome Support Group has recently been established in the North West, meeting on 17th October. *Contact Eileen Prunster on 6445 1696 for more information.*

In the South

This group has met monthly in people's homes for the last four months, getting together to watch an address by Temple Grandin at the NZ Conference and to share experiences and information. *Contact Rosanne Lay on 6244 2540 (evenings) for further information.*

Disability Discrimination Legal Advocate

Sharyn Newman is the Disability Discrimination Legal Advocate for Tasmania, based in Launceston.

Part of Sharyn's statewide role involves supporting parents in addressing concerns relating to Tasmania's inclusion policy, in particular that students with disabilities in regular schools are not receiving adequate funding and resources to fully participate in the classroom.

Presently, Sharyn is seeking to collect information about the difficulties faced by school aged children and their families, in order to raise these issues with the

Minister for Education.

If you would like to discuss problems or experiences with the inclusion policy, or have any queries, Sharyn can be contacted at :

The Launceston Community Legal Centre Inc.
4a George Street
PO Box 1582
Launceston TAS 7250
Phone : 6334 1577
Fax : 6331 5237
Free Call : (1800) 066 019

Holiday Respite Service

Staff Connections is a specialised Staffing Agency operating on the Gold Coast that provides temporary/relief staff to services for people with a disability.

One role of the organisation is to provide support to people with a disability and/or their families who visit the Gold Coast on holiday. Families are able to access respite according to their own needs, thus avoiding the costly alternative of providing their own support worker for the duration of the holiday, when such a person may only be required at certain times.

The service is able to provide support at varying levels, from two hour personal care to full day or overnight support. It is not centre based but can assist families to tap into such services as required.

The *Staff Connections* team consists of experienced people working within the disability field (including autism spectrum disorder) who are carefully matched to meet the individual's/family's needs.

For further information about this service contact :

Angie Elmes
Co-ordinator
Staff Connections
Suite 115/15 Albert Avenue
Broadbeach QLD 4218
Phone/Fax : (07) 5527 7716
Mobile : 0411 231 198

Book Review

The Communication Skills of Children with Autism Spectrum Disorders

Kate King, Speech Pathologist, Autism Association of South Australia, Inc.

This manual was written by Kate King, longtime Speech Pathologist with the Autism Association of South Australia, through funding from the Disability Services Office of South Australia.

Consisting of three parts, this excellent resource draws on Kate's years of clinical experience in addition to an extensive review of recent literature to provide parents and professionals with an extremely comprehensive guide to communication difficulties in those with autism spectrum disorders.

Part 1 provides an overview of autism spectrum disorder, its aetiology and history, including specific information relating to Asperger syndrome. A definition of communication follows, introducing the reader to basic terminology and concepts as a base for later, more autism-specific discussion. Lastly, neurological difficulties associated with autism spectrum disorders - in particular motor planning problems - are discussed, again drawing on recent research findings and clinical experience.

Part 2 outlines communication development in great detail, with chapters relating to pre-language skills (including intentional communication, language functions, gestures and imitation, play and oral skills), symbolic communication (including concept development, pragmatic skills, echolalia and differential diagnosis of autism versus specific language impairment) and non-verbal communication.

Part 3 is overflowing with practical ideas to assist individuals with autism spectrum disorder develop their communication and play skills. It includes discussion relating to different ability levels and ways to more specifically adapt intervention strategies for adolescents and adults. A chapter on augmentative and alternative communication outlines the various options, suggests ideas to try, and will assist the reader in the decision making process.

In light of the high cost of so many autism texts and resources, it is refreshing to discover a manual that

combines such outstanding theoretical and practical content with a price well within reach.

The Communication Skills of Children with Autism Spectrum Disorders is available through the Autism Association of South Australia (on (08) 8379 6976) for \$25 (includes postage and handling).

Rachel Evans

What's New in the Library

The following are our most recent additions to the Autism Tasmania library which operates from the north, north west and south of the state:

- **'Thinking in Pictures - and other reports from my life with autism'**
by Temple Grandin (1996), Vintage Books, New York
(one copy to each region)
- **'Sibshops - Workshops for Siblings of Children with Special Needs'**
by Donald Meyer and Patricia Vadasy (1994), Paul H Brookes Publishing Company, Inc., Baltimore. As reviewed in the June, 1998 edition of *Autism News*
(one copy to the northern library)

To access the library in your region contact:

- North : Trish Bourke (6331 6168)
North West : Michelle Williamson (6442 4079)
South : Rosanne Lay (6244 2540)

AUTISM BOOK SUPPLIERS

Open Leaves Bookshop
71 Cardigan Street, Carlton, VIC 3053
(Phone (03) 9347 2355)

Therapy Co-ordinates
165 Melville Road, West Brunswick, VIC 3055
(Phone (03) 9383 7277)

<book in hand>
16 Jumbuck Street, Jindalee, QLD 4074
(Fax/Phone (07) 3279 0678 or
email blackman@eis.net.au)

Autism Spectrum Disorder and the Net

The Internet houses a wealth of information relating to autism spectrum disorder. The following is only a selection of the many web sites on offer, however any site will list additional connecting sites relevant to the topic. Thank you to John Wigg and Lisa Sherrin for providing the following list:

- **Centre for the Study of Autism**
<http://www.autism.org>
 Information for parents and professionals, links to many other resources, outlines research on the efficacy of various therapeutic interventions.
- **The Autism Research Database**
<http://osiris.sunderland.ac.uk/aut-cgi/homepage>
 email: aru@sunderland.ac.uk
 A site at the forefront of research into dietary and immune system problems.
- **Autism Research Institute**
<http://www.autism.com/ari>
 Headed by long-established and at times controversial expert, Dr Bernard Rimland.
- **Autism Society of America**
<http://www.autism-society.org/>
 This site includes an article by Temple Grandin on autistic emotions.
- **The National Autistic Society**
http://www.oneworld.org/autism_uk/index.html
 email: nas@mailbox.ulcc.ac.uk
- **Autism-Europe**
<http://osiris.sunderland.ac.uk/autism/eur.html>
 email: AUTISM.EUROPE@arcadis.be
 This organisation has done valuable work in advocacy and human rights for people with autism. Papers from a recent conference also on the Web.
- **Autism Resources**
<http://web.syr.edu/~jmwobus/autism/>
 An exhaustive list of online information/resources on autism and Asperger Syndrome
- **The Autism and Asperger's Syndrome Independent Living Association**
<http://www.amug.org/~a203/>
 A massive site of resources provided by people with autism and Asperger Syndrome.
- **Paris' Place**
<http://www.accessin.com.au/~paris/dataajs/autism.htm>
 An Australian site full of useful information on autism spectrum disorder.
- **Asperger Syndrome**
<http://www.ozemail.com.au/~prussia/asperg03.htm>
 Australian site offering a range of information and support group contacts.
- **Diagnostic Information on Asperger Syndrome**
<http://www.ummed.edu/pub/o/ozbayrak/aspcrit.html>
<http://www.udel.edu/bkirby/asperger/>
<http://www.btinternet.com/~witwicki/page2.html>
- **Therapy Approaches**
Sensory Integration International -
<http://home.earthlink.net/~sensoryint/>
American Music Therapy Association -
<http://www.namt.com/>
Recovery Zone (ABA) -
<http://pages.prodigy.net/damianporcari/recovery.htm>
Society for Auditory Integration Techniques - <http://www.sait.org/>

National Autism Week

15th -23rd May, 1999

Do you have any ideas for next year's celebration?

Please contact a committee member

Charter for Persons with Autism

People with autism spectrum disorder should share the same rights and privileges enjoyed by all of the European population where such are appropriate and in the best interests of the person with autism.

Those rights should be enhanced, protected and enforced by appropriate legislation in each state.

The United Nations declarations on the Rights of Mentally Retarded Persons (1971) and the Rights of Handicapped Persons (1975) and other relevant declarations on Human Rights should be considered and in particular, for people with Autism Spectrum Disorder the following should be included:

- 1 **THE RIGHT** of people with autism to live independent and full lives to the limit of their potential.
- 2 **THE RIGHT** of people with autism to an accessible, unbiased and accurate clinical diagnosis.
- 3 **THE RIGHT** of people with autism to accessible and appropriate education.
- 4 **THE RIGHT** of people with autism (and their representatives) to be involved in all decisions affecting their future; the wishes of the individual must be, as far as possible, ascertained and respected.
- 5 **THE RIGHT** of people with autism to accessible and suitable housing.
- 6 **THE RIGHT** of people with autism to the equipment, assistance and support services necessary to live a fully productive life with dignity and independence.
- 7 **THE RIGHT** of people with autism to an income or wage sufficient to provide adequate food, accommodation and the other necessities of life.
- 8 **THE RIGHT** of people with autism to participate, as far as possible, in the development and management of services provided for their wellbeing.
- 9 **THE RIGHT** of people with autism to appropriate counselling and care for their physical, mental and spiritual health; this includes the provision of appropriate treatment and medication administered in the best interest of the individual with protective measures taken.
- 10 **THE RIGHT** of people with autism to meaningful employment and vocational training without discrimination or stereotype; training and employment should have regard to the ability and choice of the individual.
- 11 **THE RIGHT** of people with autism to accessible transport and freedom of movement.
- 12 **THE RIGHT** of people with autism to participate in and benefit culture, entertainment, recreation and sport.
- 13 **THE RIGHT** of people with autism of equal access to and use of all facilities, services and activities in the community.
- 14 **THE RIGHT** of people with autism to sexual and other relationships, including marriage without exploitation or coercion.
- 15 **THE RIGHT** of people with autism (and their representatives) to legal representation and assistance and to the full protection of all legal rights.
- 16 **THE RIGHT** of people with autism to freedom from fear or threat of unwarranted incarceration in psychiatric hospitals or any other restrictive institution.
- 17 **THE RIGHT** of people with autism to freedom from abusive treatment or neglect.
- 18 **THE RIGHT** of people with autism to freedom from pharmacological abuse or misuse.
- 19 **THE RIGHT** of access of people with autism (and their representatives) to all information contained in their personal, medical, psychiatric and educational records.

Presented at the 4th Autism-Europe Congress, Den Haag, May 10th 1992

(Continued from page 3)

word 'association' had to be deleted, special permission (and payment) granted for it to be used. The majority of delegates favoured 'autism' as the first word in the title - denoting the group's focus. The final decision was made, the new name being 'Autism Council of Australia' which all felt encapsulated our role as a council of people meeting to further the cause of Autism Spectrum Disorders within our country.

Among other items on the agenda were the Health Disability Interface, Evaluation of the commonwealth Disability Strategy and discussion of a Trans Tasman Relationship. Tasmania suggested that we discuss the CHAT List and its implications as a screening tool. Delegates were in agreement that each state should be free to use it as deemed appropriate, once its status concerning copyright is clarified.

Tasmania's recent public services announcement, shown on commercial television during National Autism Awareness Week, was viewed by all delegates and received much praise for its content and clarity of information.

National Autism Awareness Week for 1999 will be from 16th to 22nd May and it is hoped we can really make it a national event.

Once again each state presented its Annual Report and it was fascinating to learn about each state's funding and service provision. These reports are available to anyone interested in reading them.

It was a very busy two days and a valuable time to meet with others who are working towards raising the awareness of Autism Spectrum Disorders.

Rose Clark

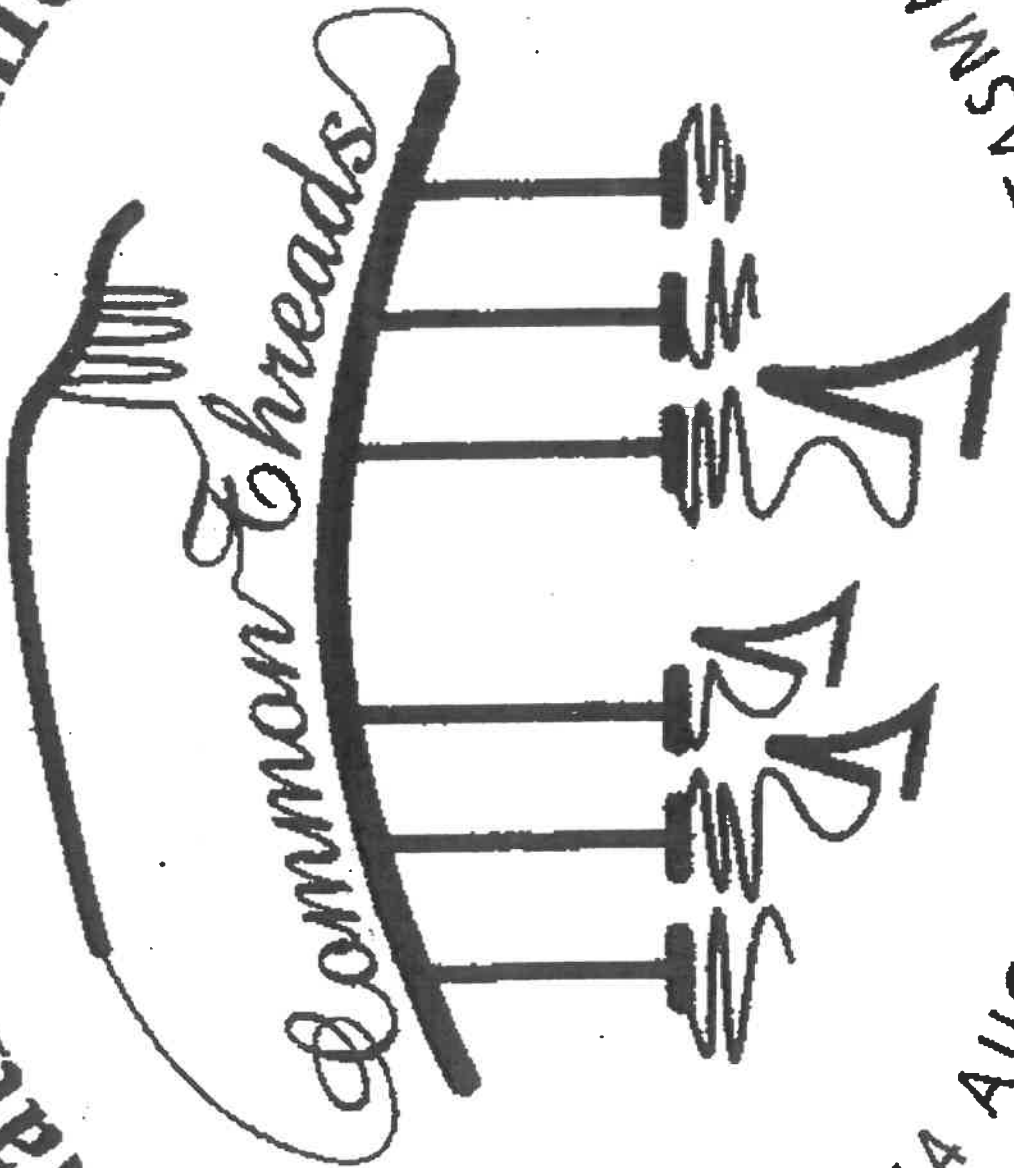
Coming Events

There is plenty happening between now and the end of the year, so add the following dates to your calendar!

- **Autism Tasmania North West Get Together**
Old, new and prospective members, and anyone interested in autism spectrum disorder, is invited to get together at the Early Special Education Centre, Beaufort St, Somerset on Saturday, 31st October, 1.30 - 3.30pm. Please bring a plate to share.
Contact Liz Maddern on 6435 2021, or Rose Clark on 6423 1086.
- **Asperger Syndrome Support Groups**
Contact the following people to find out about meetings in your area:
North : Rachel Hodge (6393 7183)
North West : Eileen Prunster (6445 1696)
South : Rosanne Lay (6244 2540)
- **Young Autism Support Tasmania (YAST)**
(Supporting Families Teaching Applied Behavioural Analysis)
YAST meets on the 3rd Wednesday of each month at Albeura Street Primary School, Hobart at 7pm.
Contact Grace Talbot on 6229 7818.
- **National Respite Conference, Melbourne, 11th-13th November, 1998.**
Contact the Association for Children with a Disability on (03) 9500 1232.
- **NSW State Autism Conference, 'Positive Partnerships'. University of Technology, Sydney, 14th-15th November, 1998.**
Keynote Speaker Linda Hodgdon (US), Speech Pathologist and specialist in addressing communication needs of students with autism.
Contact Chris O'Connell-Gray on (02) 9452 5088.
- **Autism Tasmania December Newsletter Deadline 20th November**
- **'Artistic Eye' Exhibition, National Gallery of Victoria, 14th November to 13th December, 1998.**
Exhibition of art works by children and adults with autism spectrum disorder.
Contact Amanda Golding on (03) 9885 0533.
- **Southern Cross Special Children's Christmas Party, Hobart 13th Dec, Launceston (date to be confirmed).**
If you require a ticket for your child and your child's school is not allocated tickets:
Contact Linda Jones, PO Box 873, Launceston, 7250.

1999 National Autism Conference

Common Threads



12-14 AUGUST 1999, HOBART TASMANIA

This is the logo and theme for next year's conference. Stay tuned for details in our next issue