



AUTISM NEWS

Newsletter of Autism Tasmania Inc.

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Australia

*Merry
Christmas!*

Edition 37
December 2001

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BRANCH BUSINESS

Meet the new President: Rachel Hodge

Welcome, this is the first Presidents report since my election as president at the AGM in September.

For the many that don't know me I would like to introduce myself, I am the mother of 3 sons, the eldest with a ASD disorder, a teacher with interest in special education and as a believer in the rights of everyone to fulfill their potential. I have been a committee member for the past 3 years and look forward to the challenge ahead in times of change.

It is also the time to thank Rose Clark for her tireless efforts over the past years. Rose stepped down in September as President and remains a much valued committee member in 2002. Rose has given of her time and expertise for many years and has helped many in the roles of parent supporter, manager, organiser and teacher to name a few. We look forward to her invaluable contribution in the time to come.

The year has flown past and it is hard to believe that once again we are approaching Christmas and the start of a new year. For the committee of Autism Tasmania the year has been busy and one of change.

And as we move forward we find ourselves at a crossroad with decisions to make about our future direction and goals. Under the strong leadership of past presidents, Mark Ward and Rose Clark, and the work of past committees, we find ourselves to have almost outgrown our capacity as a volunteer organisation. The goals and purposes of the organisation remain the same since its inception ten years ago and as the organisation has become more widely recognised and grown the demands on time have grown enormously.

It is for this reason that we are working towards the employment of a part-time support worker, to act as an advocate for families and

individuals with Autism. We will keep you informed as to the progress of this.

To enable the committee to be pro-active in areas of need, and to use time efficiently we are currently involved in the setting up of working parties. After brainstorming and prioritising areas of need the new committee came up with three key areas into which to concentrate efforts in the coming year.

- Assessment and Diagnosing of Autism in young children through to adulthood
- Post School Options
- Education - inclusion and accountability

The working parties are currently working on mission statements, goals and pathways for the next twelve months and will present them at the next committee meeting for ratification. We will publish the statements in the next newsletter and keep you informed as to developments. If you would like to have input, or join a working party, please contact me and I will put you in touch with the facilitator of the appropriate group.

The new committee is made up of representation from many support and interest groups within the field of Autism and consists of a balance between professionals and parents. It is the balance between interest groups, and personal and professional membership that will enable Autism Tasmania to meet the needs of individuals with ASD and educate and support the Tasmanian community about ASD.

We look forward to your continued support in the year to come, a year that promises to be as busy and rewarding as the past.

On behalf of the committee I would like to wish you and those dear to you a safe, happy, and contented Christmas and all the best in 2002.

Rachel Hodge

New Constitution Accepted

Members voted unanimously at the recent Annual General Meeting to adopt the changes to the Constitution put forward by the outgoing Committee. A highlight was the purposeful and informed discussion from the large number of members who attended. In addition to the changes explained in the letter sent to members before the AGM, several amendments were made that further improved the document and better reflected the contemporary focus of Autism Tasmania.

The document has been sent to the Business Affairs Branch of the Dept of Justice & Industrial Relations. When they confirm receipt of it, the Constitution becomes the document governing the affairs of Autism Tasmania. We expect this to be early next year.

The most obvious changes are to style and layout. The various subjects are in a logical order, wording and rules have been simplified. New rules covering the Association's non-profit principle, the logo and expulsion of members have been introduced.

At the AGM, some small changes were made to the purposes and objects of Autism Tasmania. These do not change the scope of what your Association will be doing but members took the opportunity to fine-tune the wording after nine years of reflection. For example, references to treatment were removed and the nature of potential research broadened to cover all aspects of autism spectrum disorder.

Categories of membership and the procedure for membership approval are much clearer.

- Personal membership is available to anyone over 18 years of age.
- Family membership provides each of 2 partners with personal voting rights.
- Organisations can belong, participating through a nominee with voting rights.
- Life and Honorary membership has been introduced.
- Future employees of Autism Tasmania can be members but will not have voting rights.

Membership fees apply to each calendar year, with a period of grace available for three months before

membership lapses.

Arguably, the most significant change was to increase terms of office for all Committee members to two years, with half retiring each year. The Committee's belief that this will promote stability and help develop a longer-term focus was supported by members.

From the 2002 AGM, two-year terms will be introduced. The Constitution sets out transitional arrangements to enable this to happen. The election processes will not change; members retain the ability to elect all Committee members and determine the Executive.

In any organisation, a time for reflection is important. After 9 years, this review has given the Committee and members the chance to do just that for one area of the Association. Some interesting questions were raised during the review and some of these will no doubt arise in future discussions about the Association's purpose, structure and operation. This is as it should be in any dynamic organisation.

My thanks to the Committee for entrusting me with the project and for your open and interested participation. Thank you also to those members who discussed issues with me, put points of view and attended the AGM.

Mick Clark

Committee Members of 2002

President Rachel Hodge	molly@microtech.au.com	6344 3261
Vice President Sue Thorogood	suenandy@telstra.easymail.com.au	6262 2698
Eileen Prunster	n/a	6436 3230
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Treasurer John Christie	jandme@qctas.net	0418 657 492
Committee Members Paula Barnes Rose Clark Rosemary Rush Maurice Hogan, Amelia Bishop	porl2811@hotmail.com micknrose@vision.net.au rushm@netspace.net.au mhogan@vision.net.au akenny1@vtown.com.au	6423 1086 62 295760 63 265598

Below is the PRESIDENT'S REPORT delivered at the 2001 AGM

The past twelve months have been extremely busy for Autism Tasmania providing us with many challenges and rewards. As the knowledge of Autism Spectrum Disorder grows so does the range and complexity of issues with which we are involved. Autism Tasmania is now readily acknowledged by the wider community as the umbrella organisation for Autism Spectrum Disorder in the State. As such, we have been invited to work in collaboration with other organisations.

We maintain representation on the Parent Reference Group (PRG) which has a direct link to SEAC (Special Education Advisory Committee). The PRG was established as a direct result of the Inclusion in Practice Review done by the Education Department in the last two years. As a result of this we have been asked for input into the re-writing of the Category A Autism Register document. The Parent Reference Group also maintains reciprocal links with the Teacher Reference Group as well and this is an invaluable asset to have with those involved in education.

Along with ABIT (formerly known as YAST) and Giant Steps we are also involved in the Working Group for the Pilot Project for Early Intervention in Autism. This is funded by the Tasmanian Government which is providing funding of \$80,000 per year for three years. The task of the Group has been a very complex one, highlighting processes which will identify children who will participate, program content, training for staff involved and location. These issues have been resolved and later in third term we may see a "pilot" of the Pilot Project running so that any modifications can take place before the program is run in each region.

During the year we have seen the establishment of the Statewide Autism Network (SAN) which has evolved because of the needs of teachers who have children with an Autism Spectrum Disorder in their class. Kathy Wilson, the Autism Consultant leads and coordinates this group and is working closely with other agencies, including Autism Tasmania to document a calendar of events for professional development in the coming year.

October 2000 saw the establishment of Autism Platform, a group of young adults with an Autism Spectrum Disorder. This group meets regularly to discuss is-

sues and topics of interest and is currently involved in collating information on Asperger Syndrome to include in our Parent Information Kit.

One of the Committee's "in-house" tasks this year has been to work on our Constitution which has been in existence since our inception in 1992. We have been ably directed and assisted by non-committee member, Mick Clark, who has helped us along the path of writing a "plain language" document which will better reflect the changing nature of our organisation.

Our web-site has also been up-dated and is nearly ready for public access. Geraldine Robertson, a committee member has given up much of her spare time to supplying the site with information, links to other useful sites and a message board.

Autism Tasmania maintains a good working relationship with Giant Steps and during the year we collaborated on the Jane Cotter Workshop entitled "Motivation, Management, Moving On." This was a very successful day for those who attended and the feedback was excellent.

We were however extremely disappointed when our original joint event, the major one for us for the year was cancelled. Carol Gray was unfortunately unable to visit Tasmania due to a family illness; her sessions are much revered by both parents and professionals.

Our relationship with YAST, now known as ABIT continues to prosper with regular exchange of information and mutual membership of the others organisation. We look forward to the next twelve months when we hope to co-plan functions that will benefit both our memberships.

An offer by AASE (Australian Association of Special Education - Tasmanian Chapter) in June to have access to a speaker from the US was a bonus we hadn't planned for. Ms Deb Hedeem, an Associate Professor with the Idaho State University presented a very worthwhile and enjoyable workshop on "Challenging Behaviours" to a very appreciative group of parents and a wide range of professionals. Both Autism Tasmania and AASE look forward to future opportunities to share resources.

Wendy Lawson, who thoroughly enjoys visiting Tasmania, visited us earlier in the year and is to return in October. Autism Tasmania's decision to subsidise

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her fee to enable other groups to hear her speak was very beneficial to many organisations around the state. The target group for Wendy's visit was those involved in assessment and diagnosis and many agencies took advantage of hearing Wendy speak from a personal perspective. For many it was a very moving experience.

A series of evenings around the State focussing on Wills and Power of Attorney with speakers from The Public Trustee proved to be very popular and highlighted the need parents have for pertinent, accurate information. Issues raised by questions showed that details from the Guardianship Board are also relevant to member families. Planning is almost complete for follow-up sessions to occur before December.

National Autism Awareness Week was launched in Westbury by the Mayor of the Meander Valley and incoming MLC for Rowallen, Mr Greg Hall, at an Art Exhibition that showcased the work of children attending Giant Steps.

A series of three consecutive "ads" featured in one of the three daily regional newspapers and created a great deal of interest. The other two newspapers featured the final "ad." These proved to be very informative and were the catalyst for many families requesting further information regarding Autism Spectrum Disorder. During the week we also had a Charitable Collection Day with people who were able to spare some time collecting at various locations around the state. Although this was fairly low-key, more than \$1000 was collected. A family day was held at Zoo Doo in the south of the state and several families and one brave individual featured in personal stories in our daily newspapers.

After our Governor, Sir Guy Green spoke so eloquently and with such empathy when opening our National Conference in Hobart in 1999 our Committee made a decision to approach him to be our patron. We are delighted that the Governor has bestowed Vice-Regal Patronage on our organisation and we are up-dating our stationary to show the Governor as our patron!

With the next National Conference almost upon us, we are happy to report that we have the final audited accounts from the conference organiser for our very successful 1999 Hobart Conference. While there are some minor financial details to be clarified, we can definitively announce that the event made a profit of \$26,000.

A fantastic result!

Less successful has been our decision late last year to rent shared office space in Burnie. Our vision was to "staff" it with willing volunteers, to provide access to members, for regional meetings and showcase our library. For many reasons, this proved much more difficult than anticipated. In June we decided to terminate the lease agreement. We are now actively investigating the employment of a part-time person.

Membership renewals have been slow despite several reminders, however at the time of this meeting we are up to 103 with a wide cross-section of paid members. There has been some natural attrition of members and those who have not renewed will be canvassed as to their reasons for non-renewal.

Our newsletter continues to be printed and distributed from a local Federal politician's office (as it has done for the past 3 years). The Committee has made the decision to mail out complimentary copies to appropriate agencies when articles pertinent to them appear. For example, we sent all primary, secondary schools and colleges the newsletter when we ran the article on "Bullying."

Knowledge of Autism Spectrum Disorder continues to grow in Tasmania but our knowledge base remains quite narrow. Autism Tasmania has approached the Menzies Centre for Population Health Research to consider conducting research in Tasmania into Autism Spectrum Disorder. A well conducted study which shows the location of those with Autism, their ages and needs will provide information to support our calls for much needed services to those people with an Autism Spectrum Disorder.

The work the committee has done over the past twelve months has been considerable and there are many challenges ahead. As well as the research mentioned, our expanding agenda encompasses the needs and services for the young, adolescents and adults, those with a dual diagnosis, psychiatric services as well as the many issues we are already aware of!

In my closing year as President, I extend my thanks to all the elected Committee members and visitors who have given their "spare" time so freely. I wish the incoming Committee every success for the future.

WHAT'S BEEN HAPPENING

The Autism Council of Australia (ACA)

Immediately following the National Autism Conference in Adelaide the ACA held both its AGM and Committee Meetings – both these meetings took place on Monday 1st October. There were two delegates from each state, except WA who unfortunately were unable to re-book seats following the Ansett collapse. The delegates from Tasmania were Sue Thorogood and Rose Clark.

The AGM was the shorter of the meeting re-electing the office bearers: President – Dr Lawrie Bartak (Vic), Vice-President – Amanda Golding (Vic), Treasurer – Paul Power (NSW), and Secretary – Rose Clark (Tas).

The Committee of the ACA had a very large agenda including looking at the national priorities for the ACA. The meeting decided to investigate establishing a National Secretariat with an employee whose sole job it would be to fundraise (including salary) and to look after the National scene advised by the ACA. A working party is currently looking at this issue and will report back to delegates during a tele-conference to be held at the end of November. Within the topic of national priorities were included national research, a national web-site and promoting awareness of ASD on a national basis.

Also discussed was the Constitution of the Association, which contains quite a few anomalies and again a working party was established to investigate and obtain legal advice.

The committee discussed National Autism Awareness Week and made a decision that it would be at the same time every year – which allows forward planning for state organisations. National Autism Awareness Week will begin on the second Sunday in May each year.

The meetings were thought provoking and there was some very lively discussion.

Rose Clark.

Parents Reference Group (PRG) Report from Rosemary Rush –

The last PRG meeting was held at Campbell Town on the 12th October. Rael Picot and Carolyn Rennie attended representing the Education Dept.

Rael Picot, in her capacity as Project Officer, explained the features of a current competency-based training program and certification for aides. At the time of the last PRG meeting the outcome of an incentive package of \$4000 for schools for each aide trained was not known.

The package is funded from "Learning Together" which is Commonwealth funding. There are four certificate levels. Working with students with a disability comes in at the fourth certificate level. This training program will be significant in raising awareness for the necessity of adequately trained aides for children with disabilities and also give due recognition to those that serve our children well.

The PRG hopes to participate in a planned Principals' Conference in the near future. A panel including parents will bring attention to the essential elements of how a family assists their child at home and in the wider community. PRG believes that this 'up close and personal' approach will be effective in raising awareness among principals in our state.

Our final meeting for this year is planned for 7th December.

Rosemary Rush – Committee Member

Disclaimer

The opinions expressed in this Newsletter are those of the writer and do not necessarily reflect the views of Autism Tasmania Inc.

Any mention of products or treatments does not constitute an endorsement.

The Editor reserves the right to follow normal sub-editing procedure.

REPORT FROM ABIT - AUTISM BEHAVIOURAL INTERVENTION TASMANIA - FORMERLY YAST

In August this year our support group for families teaching ABA - applied behavioural analysis - celebrated five years together. We have grown significantly in numbers and expanded considerably in the nature of the supportive work that we do, but our "core" aim remains the support of families teaching their children in home-based ABA programs.

Because ABA has been identified in the research literature as the most effective form of early intervention for children with ASD, our second main aim is to lobby for government funding of intensive early intervention programs such as those already funded by the Western Australian Government and ideally like the fantastic programs already fully funded in Norway. We are hoping that all teachers and teacher aides will ultimately become skilled in the techniques and practices of ABA in order to meet the very specific needs of the individual children with ASD included in their classes.

At the time of our AGM held in August, YAST members voted to change our name to Autism Behavioural Intervention Tasmania, to be known as A.B.I.T. We made the change from the former name in order to be much more 'locatable' in phone books and directories and also to clearly indicate the focus of our group. By being ABIT our name parallels the names of our sister organisations in other states and paves the way to a national group of ABA specific organisations.

We have a much larger committee now and this should make it much easier to respond to the needs and requests of our members. We invite requests from members and from the wider autism community if there is a speaker you would like us to organise. We pride ourselves on our open decision-making processes and remind members that although we tend now to give just brief updates of committee work at support nights, anyone is welcome to come along to our open committee meetings.

We continue to be represented on the PRG - the Parents Reference Group to the Education Department's Special Education Advisory Committee - as is Autism Tasmania, as well as being represented on other Education Department groups such as the Working Parties for the Autism Pilot Early Intervention Project, Special

Schools and IEP's.

We are hoping that the Education Departments' Pilot Early Intervention Program will exemplify best practice, although for various reasons, the progress of this working party has not been as rapid as we had hoped.

Diagnosis and therefore early identification of children at risk of Autism remains a huge problem in Tasmania as our birthrate of approximately 6000 children per annum would, one expects, mean that at least 12 children per year could be born with autism with a further 48 or so on the spectrum. As the ABIT representative on the EI Pilot Working Party, I was concerned at the last Pilot meeting to learn that only a very small number of children have been identified so far for the pilot.

Rose Clark and I met with senior nurse managers and other senior staff in the Department of Health and Human Services to discuss the need for early identification of children and we are looking forward to the time when "clinic sisters" receive further PD in ASD.

On the issue of diagnosis, ABIT is pleased to learn that the Southern Division of General Practice will include a module on developmental disability in its PD plans for GPs over the next few years and we have offered to provide input into planning for this.

In terms of practical support for families, I am pleased to report that we held a successful bowling day for siblings in the September holidays and were pleased to subsidise siblings sessions held recently by ABAKidz during Wendy Lawson's visit.

On January 16 2002 we will be holding a beach picnic for families and we hope that all our children including siblings, along with parents will benefit from the sharing on that day.

I recently attended a session on supporting siblings held at Calvary Rehab and was given an information package which is now in our ABIT library. The most recent research into siblings and disability indicates that the single most important factor in the long term is the provision of on-going contact with other siblings in similar situations. So, I hope that our family get-togethers go some way towards providing that. We welcome any suggestions for other sibling events.

We have asked Autism Tasmania to look into the

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criteria for funding Commonwealth Respite for Carers as we hope that some reforms might be made to extend support to siblings as well as beyond purely educational sessions for parents and carers.

As I write this (21 November), I am getting organised for our regular monthly support night tonight - a video night. We still meet on the third Wednesday of the month in the comfortable setting of member's homes although we will be eating out at La Porchetta's restaurant in North Hobart on December 19 and will skip the night' in January, opting for the beach picnic instead.

Our first support night in February will be held at Sal's restaurant in Salamanca Place on the 20th Feb and our second meeting will be at the home of Anita Killick, 12 Allambee Crescent, Glebe, ph 62 311021 on March 20 2002.

ABIT still partially subsidises the costs of clinical psychologist Jura Tender's visits to the state and reminds members that Parents Review nights are FREE to all members whether they are clients of Jura's or not. Jura will be back in Tasmania in early December.

Our indefatigable Secretary, Rosemary Rush has set up a mutual support effort whereby members are matched to provide more 1:1 support. Please contact Rosemary 62 295760 <rushm@netspace.net.au> for more information.

Our support nights have been very well attended this year and we are keen to respond to our members' needs so don't hesitate to ask if we can help you.

Remember, ABA should be fun !!!! and I hope that everyone, our children with ASD, their siblings, we parents, therapists and other professionals and supporters can have some wonderful moments of fun over the summer too. Take care and a Merry Christmas to all, Lisa Minchin,

President, ABIT ph 62 232317
<d.minchin@bigpond.com

Guardianship Board Seminar

Unfortunately, the recent seminar on the Guardianship Board had to be cancelled due to poor numbers.

If there is demand from the members, it may be rescheduled in the future.

As a courtesy to our voluntary committee, we do

ask that members adhere to RSVP dates, so that we can proceed or cancel seminars with an accurate idea of numbers and not have to cancel functions at the last minute.

Cheryl Scott Secretary

Pilot Study Project. Report from Rose Clark

Unfortunately I was unable to the last meeting in Hobart due to work commitments, however as most of the decisions have been made regarding this project, it was not a crucial meeting. The minutes have been forwarded to me by Kathy Wilson (Autism Consultant) and the most important aspect of the project is that shortly a "pilot" of the Pilot Project will be run in the south of the state so those involved with the program planning can view it before the Pilot runs on a larger scale. The locations for the program are very important and for this reason Early Special Education sites are going to be used. We will keep you up-to-date with this project as it has exciting prospects for the future for our younger children.

Rose Clark Committee Member

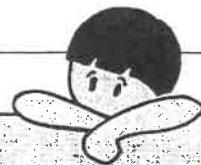
AUTISM SUPPORT GROUPS IN YOUR REGION

Autism Southern Support Group
Contact Janet Smith on ph. 62591149

Autism Northern Support Group
Contact Sue Thorgood on 63622698

Autism North Western Support Group
Contact Rose Clark 64231086

Autism Platform
South: Jan 6272 1049 and Irene 6278 2394
North: Paula 6397 3088



GIANT STEPS TASMANIA

And so we approach the end of another successful year at Giant Steps - a year which saw the commencement of our Adolescent Program, the development of a Centre in Launceston, the acquisition of two buses and the gaining of distribution rights for The Morning News in Australia.

With the enrolment of Ben whose family has recently arrived from Melbourne, our students' ages now range from 4 years to 15. Our decision at the beginning of this year to move towards a class-based organisation has proven worthwhile, allowing us to gear the curriculum more specifically for the children. However, we are still small enough to bring everyone together for a special activity.

We organise the children into three groups, allocated generally according to age. Red Group has six children: Ben comes for three days but the rest are there every day. Robyn Thomas takes responsibility for the program with input from the

rest of the Therapy team, and at least three Therapy Assistants.

Marian Quinn organises Yellow and Blue Groups, our older students, many of whom have significant time in mainstream schools. Our specialist Therapy team work in each classroom and withdraw each child for specific work as required. Katrina, Rebecca, Judy and Mary have exceptional skills working with autistic children in the areas of Occupational Therapy, Speech Pathology, Activities of Daily Living and Music.

Our program, which was originally based on the ground-breaking work of Darlene Berringer of Montreal, Canada, has evolved over the years to reflect the highly-respected philosophy of the TEACCH program of North Carolina and the Grodin Centre of Rhode Island in the USA. These centres are regarded as world's best practice and Giant Steps in both Tasmania and Sydney have adopted that direction. In February, we will have a visit from an Autism specialist from California who will work with our staff, and other Tasmanian professionals to train us in the TEACCH program. We believe this initiative and other relationships we are developing within the worldwide Autism community will be of great long-term benefit to all people in Tasmania with an Autism Spectrum Disorder. There are still part-time places available at Giant Steps next year, for both Primary and Secondary children up to 16 years of age. If your child is eligible for Category A registration, the cost will only be \$25 per day. We can even transport him or her from Launceston or Devonport to Deloraine for the equivalent of the Conveyancing Allowance; that is, at no cost to you. Giant Steps can be contacted on 03 6362 2522 or 0418

John Christie

Enrol your child at Giant Steps Tasmania

the state's only specialist Centre for
children with an Autism Spectrum Disorder

and have the benefit of regular attention
from experienced professionals:

Teachers,
Occupational Therapist,
Speech Pathologist,
Lifeskills Therapist
Play & Social Communication Therapist

and a team of trained Therapy Assistants

Giant Steps' fees are very reasonable
from only \$25 per day

Ring the Principal, John Christie
On 03 6362 2522 0418 657 492



paid advertisement

FEATURE ARTICLES

AUTISM AND COMPUTERS

In October, Dinah Murray presented a workshop in which she explained why computers are an ideal tool for people with ASD, and how it is possible to introduce them to IT.

Initially she explained that IT suits a person on the autism spectrum because the computer provides the following qualities;

- Reduced stimuli
- Visual cues
- Repetition
- Clear-cut rules
- Structure
- Predictability
- Controllability
- Unhurried pace
- Interest

Dinah also showed that IT suits people who work with individuals with ASD. The crucial points are that the computer can focus on a common interest and be a vehicle for shared fun.

Apart from being simply educational, working together using a computer can promote

- Conversation and sociability
- Creativity and playfulness
- Self-awareness and reflection
- Quite easily identified common interests
- Grounds for mutual respect
- Fun with peers and siblings, and fosters turn-taking
- Non-maddening opportunities for repetitive activities and obsessions
- Potential for inclusion and employment

What can you actually do in terms of assisting someone with ASD to make the most of using IT?

Dinah explained that at the computer together you can be a constructive companion. You need to learn enough to help, and to be able to identify software which will appeal. You also need to tune in and express your interest.

Dinah suggested using a camera to make images which are relevant to the person with ASD,

and perhaps using the Powerpoint programme to make a simple book, calendar or social story.

Dinah suggested using video records to

- See what has happened
- To share events with others
- To encourage reflection
- To promote self awareness
- She stressed that we can create our own communication system by
- Using pictures
- Using special symbol systems
- Encouraging writing at a keyboard
- Sending daily messages
- Making printouts etc.

Dinah is certainly a fan of e-mail, because of its structured method of communication, and the fact that the recipient can reply in his own time.

This was a most interesting and practical workshop for both parents and teachers.

Dinah is a lecturer in psycholinguistics from the UK. She was an engaging speaker, who illustrated her presentation with a wonderful video of some work she had done with a student called Ferents, who had shown remarkable ability to produce some computer-generated cartoon images.

Penny Cromarty

Don't forget!

Subscriptions for 2002 are due by the end of December

Your renewal form is included in this mailing

Deadline 23rd February

The deadline for the next issue of Autism Tasmania will be 23rd February. Please forward your copy to Cheryl Scott on cscott1@vtown.com.au or phone 63448015 a.h. to make alternative arrangements

PROF. B. TONGE FROM MONASH UNIVERSITY CENTRE FOR DEVELOPMENTAL PSYCHIATRY & PSYCHOLOGY talking about

PSYCHOPATHOLOGY IN CHILDREN AND ADOLESCENTS

At the AUSTRALIAN NATIONAL AUTISM CONFERENCE IN ADELAIDE IN SEPTEMBER 2001.

This extract refers to a study investigating the psychopathology in young people with autism contrasted with those who have intellectual disability.

Professor Bruce Tonge began his address by explaining that psychopathology meant emotional and behavioural problems outside the range of ordinary feeling and behavioural states. Autism, he said, has its own core behavioural and emotional features that are diagnostic of the condition but often parents were describing behaviours and emotions that appeared in excess of what one would normally expect with a diagnosis of autism. Regrettably many of these problems were met with a measure of indifference by service providers.

Professor Tonge cautioned about diagnostic overshadowing saying, professionals in the field should remember that whilst someone may have a diagnosis of autism this was not the sum total of the person. Clinicians should be aware that there may be other issues or events in the life of the person with autism which could account for behaviours and emotions and for which treatments and interventions could improve outcomes.

Continuing, Tonge said that there had been a number of studies looking at co-occurring mental health problems in higher functioning young adults with autism; these include: affective disorders (depression) anxiety; a range of psychoses including, schizophrenia and mood disorders such as bipolar disorder. There had been fewer studies in earlier years about the co-occurring mental health problems in lower functioning children. With the aid of visuals, Professor Tonge began to explain the recent findings in studies into the psychopathology in this group. He began by first explaining The **Developmental Behaviour Checklist** devised by Stewart Einfeld and himself which was used in a study comparing young people with autism with a group of children with intellectual disability. The DBC, Tonge said, can determine how severe a problem is, giving a total behaviour problem score. A score of 46 and above, for example, would indicate significant problems and alert the clinician to the person requiring some form of specialist help or

treatment. It has a variety of sub scale scores, Professor Tonge explained, these relate to a number of behaviours: disruptive; self absorbed; communication; social relating; antisocial and anxiety and depression. The Developmental Behaviour Checklist has an independently derived factor score for autism, useful possibly, to measure the value of interventions over time.

The checklist has the ability to act as an indicator of Attention Deficit Hyperactivity (not as diagnostic tool) and a measure of depression.

In addition to the checklist, Tonge said that they also looked at other information, particularly the clinical assessments of these children.

THE FINDINGS:

I am sure that for many in the audience the findings were predictable. It showed high levels of disturbance in the autistic group in the areas of disruptive behaviours, anxiety, self absorbed behaviours, communication and social relating. The score for anti-social behaviour was low. Not to confuse anti-social with social interaction, this refers to such things as stealing, lying and so forth. The total problem behavioural mean score = 62.2 clearly demonstrating that with a cut off figure of 45, these children had high levels of disturbed behaviours and emotions.

The study also found that young people with autism have these high levels of psychopathology regardless of intellectual ability, however, the lower ability children had higher scores in the areas of self absorption and social relating whereas the higher ability people had greater problems in communication skills.

The study also found that there was no difference between male and female on scores relating to emotional disturbance. Age appeared not to be a significant factor either; except in the older participants, age 13 and over.

Children with autism have high levels of attention deficit behaviours but these appear to wane with age whereas the disturbances in affective disorder get worse as the children get older.

Children who were verbal had more communication problems whereas the non-verbal child had greater difficulties relating to self absorption and social relating. The non-verbal children also had greater emotional psychopathology.

The study found that compared with Intellectual Disability, young people with autism had significantly higher levels of psychopathology. Comparisons were also made with specific syndromes, namely:

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Williams; Prader-Willi; Downs and Fragile X. This showed significantly higher disturbances for those with autism and Prader-Willi and Williams syndromes.

(more information about these studies upon request)

PROFESSOR BRUCE TONGE then asked the question: What are the implications, then for the MANAGEMENT OF PSYCHOPATHOLOGY?

Professor Tonge spoke of the need for teachers and clinicians to document interventions saying that frequently interventions were introduced but there was no method of follow up to ascertain levels of improvement or otherwise. He emphasised the need for full assessment rather than targeting just a symptom. It was, in Tonge's opinion, vital to see the whole picture. He advised looking at the following factors in assessment:

- 1 Biological
- 2 Psychological
- 3 Social and family
- 4 Identification of the type of Psychopathology

Bruce Tonge then went on to describe the sorts of considerations under each factor heading:

Biological: Consideration may be given to *epilepsy* considering 20% of young people would develop a form of epilepsy by age 21, he said. It wasn't always easy to diagnose epilepsy; often teachers would attribute the vacant look or tuning out by the child as just his autism when in fact it could be petit-mal seizures. Tonge explained that behaviours and emotions could be affected by epilepsy. He also went on to remind doctors and others of the need for frequent medication review.

Another biological consideration may be to look at the *cause of Intellectual Disability. Chromosomal abnormality* is not uncommon as evidenced in *Williams Syndrome* where there is a predisposition to anxiety. One might consider dual diagnosis; the person with Autism may also have Williams Syndrome. Crippling levels of anxiety would then be understandable, said Tonge but we should also remember that anxiety is treatable.

The professor gave other examples of biological considerations, conditions which can occur in tandem with autism, speaking briefly about *Rubella* and possible difficulties in diagnosis because of sensory problems; *Tourette's Syndrome* and high anxiety states and

Tuberous Sclerosis where it is not uncommon for people to have psychosis and thought disorder.

Before concluding his examples of biological considerations, Professor Tonge said that last but not least we should remember that there are bodily considerations. A child may have an ear infection, there could be gastrointestinal dysfunction; if a child has pain then it is likely to affect behaviour.

PSYCHOLOGICAL considerations should include a psychological profile of the child. Looking at the *Cognitive profile*, understanding their strengths and weaknesses may assist a school, for example, to present information more appropriately and in doing so reduce unwanted behaviours. It was important, Tonge said, to look at possible problems associated with *fine and gross motor skills*. Another area which may affect behaviour and emotion was the temperament of the child. As with all children, Tonge mused, there were nice children and awful children.

The *Developmental Stage* of the person must be a consideration. Autism is a developmental delay and behaviour should be seen in the context with developmental age. The behaviour may not be considered appropriate for their chronological age but for the developmental age is expected and acceptable. The professor continued by saying that transitional stages should also be a consideration when trying to determine antecedents for behaviour. Is the person moving from primary to high school? Are they reaching puberty?

SOCIAL & FAMILY issues should not be ignored in the equation. *Parental Mental Health* (Tonge was not referring to parents as a cause for their child's autism), needed to be a consideration. Parents, understandably have higher levels of mental health problems, there being no difference in occurrence rates between mothers and fathers. There was evidence to say that this was child to parent rather than parent to child, in other words the stresses of having a child with autism could greatly influence a parents' psychological health. Tonge followed this by saying that it could flow the other way too, with a child reacting to the depression of a parent. Families with a child with autism, said the professor, seemed to have higher levels of dysfunction. He talked about the impact on parents of a lack of *respite care*. He spoke also about *education* and the impact upon the family if the education was not appropriate to the needs of the child; if there was insufficient aide time and or classroom support. Due to time constraints Professor Tonge was unable to expand on many of these topics.

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PSYCHOPATHOLOGY was the next consideration of Professor Bruce Tonge, explaining a need to define what form the disturbance might take.

- 1 Depression
- 2 Anxiety
- 3 Obsessive Compulsive Disorder
- 4 Life adjustment problems
- 5 Psychosis

(b) *transient psychosis*

- 6 Impulse control

Professor Tonge spoke briefly about *psychosis* saying there was an increased risk of developing psychosis in adolescence 1:100, especially in Asperger Syndrome. He told the audience that there was also another form of psychosis, *Transient Psychosis* which may manifest in hallucinations, paranoia and thought disorder but not consistently. It may indicate early signs of Schizophrenia.

Impulse control were such things as ADHD, Disruptive behaviour and Tourettes Syndrome of which Tonge made brief reference before talking about the common occurrence of depression.

DEPRESSION, according to studies, increases as one goes into adolescence, perhaps less into young adulthood, said Professor Tonge. Depression could be managed, he said, through psychological treatments. Modified cognitive behaviour therapy was useful with those who had better language skills.

Pharmacotherapy was useful in the treatment of anxiety states, Tonge remarked. He said that people should not be allowed to suffer when treatment was available.

There was some evidence to suggest that *hyperactivity* occurred in autism and this was treatable with pharmacological, psychological and school based interventions. Treatment needed to be a collaborative approach, said Tonge.

Parent Mental Health featured significantly in this part of Professor Tonge's talk. He spoke of parents needing help with their own mental health. If parents needed treatment for depression it was nothing of which to be ashamed, he said. If they recover they are more effective, obviously. The professor concluded this item by saying he felt there was a great need for respite care for families and for support networks. He then moved onto drugs.

PSYCHOPHARMACOLOGY

Drugs, Professor Tonge said, should not be considered a quick fix, they should be part of a comprehensive assessment and management plan. He was quick to say that he never used drugs as a chemical restraint inferring that he found this sort of thing offensive. Tonge stated that it was necessary when taking drugs to establish and record a baseline from which one could follow up and assess efficacy. It was vitally important to discuss side effects with the prescribing doctor and said there was the need for regular reviews to take place.

There was some evidence to suggest that Imipramine was useful in the treatment of anxiety disorders in children but less useful in depression. The more recent SSRI's such as Prozac were useful for anxiety states, he said, but cautioned about the side effects of neuroleptics like Haloperidol and Melleril. (more information upon request).

Although Buspirone wasn't used much in Australia Tonge suggested that this could be useful for anxiety.

Depression could be alleviated using SSRIs such as Prozac, especially in adults, Professor Tonge said.

Obsessive Compulsive disorder could also be helped with SSRI's and the older drug Clomipramine.

Disruptive behaviours were treated with success using low doses of neuroleptics Naltrexone, he said, was found to be useful for self injurious behaviour.

Bipolar Disorder responded well to Lithium as it was found to be an excellent mood stabiliser.

ADHD were helped with the stimulant medications.

Concluding his address, Professor Tonge said that assessments should be put in place. The notion of management required a multi modal approach. Interventions for improving communication skills was advisable and he reminded those working with young people with autism they should look at the antecedents of behaviour. Professionals should provide help and support for parents, providing them with the skills to manage these emotions and behaviours so that they do not become entrenched.

(Disclaimer I have endeavoured to retell this accurately. If there are mistakes they are unintentional and I apologise)
Paula Barnes

**Dr Robyn Cosford MBBS(Hons)
FACNEM**

talking about Multisystem Abnormalities & Gastrointestinal Dysfunction in Autism and asking the question, "Is There A Connection?"

at the National Autism Conference in South Australia 2001

"A group of children was investigated with urinary organic acids, plasma lipids, faecal microbiology studies and urinary lactulose/manitol studies for intestinal permeability. They were found to have characteristic urinary organic acid profiles indicating tissue catabolism and metabolic blocks in the tri-carboxylic acid cycle and urea cycle. They were shown to have characteristic plasma lipid profiles indicating metabolic blocks in fatty acid metabolism. Faecal analysis revealed loss of protective gut bacteria and overgrowth of potentially pathogenic bacteria, and intestinal permeability testing indicated increased gastrointestinal permeability in a large percent of those tested."

It was Dr Cosford's intention, she said, to throw light on some of the metabolic factors behind autism.

As other studies have shown, autism is not an isolated problem, with children showing changing patterns of illness; behavioural disorders, learning disorders and most commonly developmental impairment of speech; ADD, depression and other mental health problems (and this isn't good as those with autism get older); Crohns disease, Thyroiditis, Asthma, ear infections and others. There was a reported increase in brain tumours and juvenile onset diabetes. 'So, what is going on?' asked Robyn Cosford.

Regrettably due to time constraints, Dr Cosford had to rush through some of the findings which I found somewhat disconcerting. She spoke briefly and quickly about some of the aspects of her study saying that other developmental, learning, behavioural disorders were found to be common in siblings and cousins of the children with autism but a third of the group were found not to have a family history of anything. Whilst studies show a strong genetic link for autism, she said, it could not account for everything.

Dr Cosford went on to describe prenatal, delivery and neonatal problems reported. She said 50% reported complications in pregnancy with 50% reporting

nothing untoward.

50% had delivery complications, the remaining 50% nothing. Neo-natally, there were reports of low APGAR scores, jaundice, intensive care and floppy babies in just half the cases.

Robyn Cosford then looked at the first twelve months of life and said that 50% reported having antibiotics for infections, notably otitis media. Infections were commonly linked to the streptococci organism, she said.

In the period 12 months to 5 years, 90% had treatment with antibiotics and studies suggest a correlate between Otitis Media and the development of autism.

There were other aspects to the investigation which included such things as reports by parents saying that children were developing properly until some environmental occurrence among which were such things as trauma and vaccination.

In this study, and indeed in other studies throughout the world they found most commonly gastrointestinal dysfunction, Dr Cosford said. Children were found to have either chronic constipation with massive stools, diarrhoea with frothy stool or both.

Among her findings, after a range of metabolic tests and others, it was discovered that 50% of the children had low bicarb' levels which she said should simply not happen and had huge implications for total metabolism. Other findings showed raised plasma fatty acids in these children; fatty acid oxidation very poor indeed and low cholesterol levels.

She said that omega 3 was extremely low and that low DHA had implications for brain development. Among a range of tests it was found that a large percentage of children had gastrointestinal permeability - sugars crossing the gut membrane. Two thirds had leaky gut and a third had malabsorption. Dr Cosford repeated several times that intestinal permeability is a marker for gut wall inflammation. Her studies revealed that the presence of E.coli in the bowel was significantly down and in some cases absent altogether in these children but there were massive amounts of streptococcus which causes inflammation in the gut and is known also to cause neuro-psychiatric disorders. Ammonia from the bacteria in the gut would also inflame the gut wall, she said. She spoke all too briefly about the problems with sulphation in these children

(Continued from page 14)

referring to studies by Dr Paul Shattock, who spoke at the conference about environmental factors and autism.

Before Dr Robyn Cosford quickly brought to a conclusion her brief overview of a complex study, she added how important it is to provide supplements to correct the metabolic derangement, 'to put back in', for the fatty acid deficiency. It was imperative to correct the gastrointestinal dysfunction using probiotics, digestive enzymes and nutrients. She mentioned, among others, glucosamine sulphate, chondroitin sulphate, amino acids, nutrients for sulfation and antimicrobials to eliminate gut bacteria.

Finally, Dr Cosford said that she would call it, neuro-immuno-gastro-intestinal dysfunction syndrome; that there was hope for intervention and that there is somewhere to go with all this.

In conclusion, I would like to say that I appreciated the opportunity to hear Dr Cosford speak. The combination of a snap shot of her study delivered at record speed and my lack of knowledge has resulted in a review, which doesn't do justice to the enormity and complexity of Dr Cosford's work, for which I apologise. It may serve to whet the appetite of the reader or conversely confuse but I hope it will encourage people to investigate her work for themselves.

(Disclaimer: I have endeavoured to retell this ac-

Available from Autism Tasmania

Autism Tasmania Information Kit

\$12.00 includes postage for Parents

\$17.00 includes postage for Professionals

Alert Cards \$2.00 for 12

Gold Lapel Pins \$3.00 + \$1.50pp

Asperger's Information booklet \$5.00incl pp

curately. If there are errors they are unintentional and I apologise.)

Paula Barnes

Autism Platform has published a small booklet about Asperger's Syndrome, which is now available for \$5.00 from Autism Tasmania. It will also be distributed in the Parent Information Kit



Is a Cat an Autistic Dog???

Strange questions? Not really, if you think about it. Dogs are very outgoing, accepting, personable creatures. They are easy to train, come when you call them, and unconditionally love you.

On the other hands, cats are independent creatures who keep to themselves, won't respond to their name, are difficult teach, and choose when they would like attention from you.

The education system is set up fro the dogs of the world. The dogs are the norm and easier to deal with. However, we have some cats in the world. They are not lesser animals; they are not bad animals; they are just different animals. Both are still domestic animals in the category of pets.

The challenge for professionals is to program to meet the needs of the cats, aloof, silent, and in their own world. Yet cats are lovable, teachable, and capable of extraordinary things!

AUTISM. Not wrong; not bad; just different. And wonderfully intriguing!

Source " The Source for Autism", Gail J Richard, Lingui T Systems, Illinois, 1997

BOOK REVIEW

Book Review. "Understanding and Working with the Spectrum of Autism – An Insider's View." written by Wendy Lawson and Published by Jessica Kingsley Press.

This new book by Wendy released earlier this year is a must read for those with an interest in Autism Spectrum Disorder and those working with people in education and caring situations. Wendy addresses the general concepts of The Spectrum of Autism, issues related to stress and a very informative section entitled "Ideas for Action." This section covers practical implications and interventions, social understanding and social stories and language. The last section of the book includes "Questions I Have Been Asked", Commonly Asked Questions about Autism and the criteria for the assessment of Autism.

In the introduction Wendy writes about: *"What this book is not.* This book is not about applied behaviour analysis, although such interventions can work well with ASD (see Maurice 1996), not is it about aiming to make an individual with ASD more socially acceptable and able to 'fit' into their environment. Rather, it is about realising the differences between the two worlds of the neuro-typical and autistic experience and, therefore, building a bridge between them, enabling mutual exploration."

Professor Margot Prior of the Department of Psychology at the Royal Children's Hospital in Melbourne, wrote the foreword for Wendy's book and she eloquently writes the following:

"Throughout the book the themes are focused on practical issues and illustrated with case histories, and sometimes with some of Wendy's own insightful and eloquent poems. The book concludes with 'commonly asked questions about autism', followed by direct suggestions, practical exercises, and strategies which can be helpful for managing difficult behaviours. Despite the fact that we are still searching for the causes of autism, we have made encouraging progress in diagnosis, early intervention, and education for children with this condition. Wendy makes a further contribution to our knowledge which is especially valuable because of its basis in her experience of a life lived with this condition.

This book will speak directly to parents and others wanting to find ways into the world of the person with autism. It is driven by first-hand experience, excellent analytic skills and substantial experience in sharing knowledge with people working in the field. One of its strengths is its focus on understanding the connections between behavioural problems and inner stress, along with the sensible ideas and recommendations for management of problems. Wendy is a wonderful builder of bridges between the world of the person with autism and the conventional world. Her book will help many people in both worlds."

Wendy's book is available from good book stores (or can be ordered) and sells for \$39.95.

Rose Clark

Junee Waites Visit

Junee is visiting Tasmania in late January and early February 2002.

There will be an opportunity for you to meet Junee at an Autism Tasmania function.

We have several copies of her book *Smiling at Shadows* for sale @\$29.95 plus \$5.00 postage

Contact Sue Thorogood on 6362 2698 if you would like to purchase a copy.

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