



AUTISM NEWS

Newsletter of Autism Tasmania Inc.

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Australia

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FROM THE PRESIDENT

Welcome to a winter edition of our newsletter. We have included many interesting articles for you to read – hopefully in a cosy place with a nice relaxing drink.

One of our leading articles outlines what “Parent Power” can achieve for your child and how those involved can become more Autism aware and have a greater understanding of Autism Spectrum Disorder. The author of “Smiling at Shadows” did just that and in this extremely readable book,(I found it very hard to put down) showed just how her positive attitude achieved extraordinary results for her son Dane and others who followed.

We are very excited to announce that Sir Guy Green, the Governor of Tasmania has consented to be our patron. Autism Tasmania approached the Governor to be our patron in light of his wonderful opening address at the National Biennial Autism Conference held in Hobart in 1999.

Conference time is fast approaching with the next to be held in Adelaide in September. Please read the article regarding the conference and the offer available to personal members. It is a wonderful opportunity to hear some wonderful speakers and to also meet some very interesting people. Many friendships between parents have had their beginnings at get-togethers such as this.

National Autism Awareness Week has again been held in Tasmania with an art exhibition, button day, newspaper articles and an insert in all papers aimed at educating the public about Autism Awareness Week. We have been asked by new parents and extended family members why we do not have a “day” which is as noticeable as “red nose day.” The answer is nobody has come up with an idea which would involve the public in a similar way. **HOWEVER** if anyone reading this newsletter has an idea that they would like to share

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with us, please let us know. I firmly believe there is an idea out there just waiting to happen.

The committee of Autism Tasmania has been working on remodelling the constitution to better reflect the organisation as it is now - as we have grown the constitution has shown some inadequacies. Giving us some valuable help with this task is Mick Clark, who has had experience in this field with another organisation. The modified constitution will be distributed to all members before our next AGM, where it will be on the agenda to be ratified.

Over the next six weeks there will be functions in all areas of the state, we hope to see YOU at one of them.

Rose Clark

NATIONAL AUTISM AWARENESS WEEK.

During the week of May 12th - 19th Autism Tasmania organised various activities for National Autism Awareness Week. These activities were circulated to all members by a flier. Each region had a social night where members could get together and some of us enjoyed the company of other members with a convivial drink. In the north the week was launched by the Mayor of the Meander Valley and newly elected Legislative Councillor, Mr Greg Hall at a retrospective art exhibition organised by Giant Steps in Westbury. The evening was attended by about 30 people who enjoyed drinks and a light snack and then ventured onto a meal at Hob Nobs.

On Friday, May 18th quite a few people collected donations from members of the public for our Button Day. We had representation in Ulverstone, Devonport, Deloraine, Launceston and Kempton in the South and although the exact amount has not been tallied we collected well over \$1000. A big thank-you goes to all those who helped, some of whom are not members of Autism Tasmania.

On Saturday 19th families were invited to attend Zoo Doo in Richmond. This venue provided the children with the opportunity to have as many rides on the equipment as they liked, spend as much time on the jumping caste as they desired and the exciting experience of a trip on the "train/bus" to feed the emus, ostriches, camels, deer, sheep and goats. Those who attended discovered the bad manners of the imported ostriches, but found that Australia's emus had no such deficits! Once over the shock of both these birds putting their heads into the train/bus we discovered that the camel liked to be fed this way too. There was much hilarity and both children and adults found this activity very interesting. Although attendance at this venue was disappointing, we found the staff at Zoo Doo attentive and supportive when showing our children around.

During the week, Autism Tasmania had a series of educative "ads" in the Examiner and the final one of these "ads" was placed in both the Advocate and Mercury on Friday 18th. Since these have appeared in the newspapers, we have had a great number of phone calls asking for information. The Advocate and the

Examiner have both printed articles on families who have a member with an Autism Spectrum Disorder and both these were well written and informative. Thank-you to those people who featured in these articles, we appreciate your help. Temple Grandin featured in a wonderful documentary on SBS at the end of the week. If anyone wants further details please contact me. Rose Clark

PATRON.

Since the inception of Autism Tasmania in 1992 we have often discussed the issue of having a patron. Up until recently there has not been a person who we felt "fitted the position." However after the opening address at the National Biennial Autism Conference in Hobart we felt that our Governor, Sir Guy Green had a great understanding of the difficulties when talking about Autism Spectrum Disorder. His speech had a great amount of empathy as he spoke about the issues of service provision and those who come into contact with people with Autism.

Earlier this year we wrote to the Governor asking him if he would consider being our patron and to our great delight he accepted our invitation. We look forward to a long association with Sir Guy Green.

MEMBERSHIP RENEWAL

We'd like to thank those of you who have renewed your membership for another year. As you will see in this newsletter, members have the opportunity to apply for a fully paid trip to Adelaide to attend the National Biennial Conference. Members also have the offer of childcare to attend the seminar on Challenging Behaviour to be held in Launceston on June 19th. (You should already have received a flier about this.)

If you have not renewed your membership you will receive a reminder in the mail in the near future. We understand that you may have put the form aside to deal with later and it was mislaid in the Christmas rush. Memberships received by July 7th will enable those people to apply for the Adelaide Conference offer.

CAN YOU HELP?

Autism Tasmania runs many seminars and workshops each year – often with internationally regarded speakers. We (the committee) endeavour to make these activities as widely available as possible to the Autism Community and the agencies which support it.

We send out hundreds of fliers each year advertising our various activities to as many agencies (eg schools, child development units, therapists etc and families as we can find - depending on the subject matter.

It is frustrating that our intended audience does not always receive our information ,or receives it in time to take advantage of it.

Maybe you can help us?

All of us know individuals within agencies who would benefit or would be interested in furthering their knowledge of Autism SD. Whether that person is your GP, Paediatrician, Disability Services case worker, Respite Carer, Teachers Aide, Teacher, Special Ed Teacher, or the CDU professionals who helped with the initial diagnosis – it doesn't matter. Anyone! If you know of anyone who would appreciate an individual invitation to Autism Tas Seminars — let us know and we will send them out an invitation .

Give us their name, role, agency, phone number and or fax number and we'll do the rest

Many thanks. Your hard working committee

COMMITTEE MEETING

Our last Committee meeting was held on May 5th in Hobart at the home of our Treasurer, Amelia Bishop. Nine committee members attended. Amelia was a very hospitable hostess, keeping us fed and watered throughout the day. Thanks Amelia.

The most urgent item of business was finalising our Autism Awareness Week functions. Other issues included the program for our seminars and workshops, which is filling out well and

we have functions being planned well into the second half of the year.


Jan Mahoney has unfortunately tendered her resignation and it has been accepted with regret.

Quite a bit of time was spent discussing future directions for Autism Tasmania. These included revising our constitution, our relationships with Autism service providers in Tasmania and the purpose and possible funding of a paid position in Autism Tasmania.


Scattered throughout this Newsletter are the three Advertisements we ran during Autism Awareness Week.. They were run over consecutive days in The Examiner and the third one was run in The Mercury and The Advocate on the last day.

Cheryl Scott – *Minutes Secretary*

What is it that adds to the genius of Mozart, but for others means that they will need 24 hour care for the rest of their lives?



What is it that allows some people to make extraordinary contributions to society, yet prevents others from participating in it fully?



Answer tomorrow:

Appeared in *The Examiner* on Wednesday 16th May 2001

FOR YOUR INFORMATION PILOT STUDY NEWS.

As reported in the last newsletter, small working parties were looking into various programs to look at best practice in Early Intervention Programs. After two more meetings recently, the Working Party is now considering when programs will be implemented into Early Special Education settings.

It is very important to ensure the program delivered to the children will suit each of their individual needs and that staff are trained adequately to ensure the consistency of the program across the state. Another meeting is scheduled for early second term when the staff training schedules have been drawn up. This task is being undertaken by Kathy Wilson (formerly Gill) who is the Autism Consultant within the State Education Department .

PARENT REFERENCE GROUP.

Unfortunately there is nothing to report regarding this group which was established as part of the recommendations from the Inclusion Review. Chairperson for the group, Mrs Susan Rockliff has unfortunately left the state with her family because of her husband's work commitments and so far she has not been replaced as chairperson. She held the position of President of the Tasmanian Council of State Parents and Friends Association. The Parent Reference group was working towards many of the issues which came out of the Inclusion Review and it is hoped that it will be reconvened very shortly.



WHAT'S ON?

Seminars/Workshops. Carol Gray Cancellation

Unfortunately, Carol Gray has had to cancel her New Zealand & Australian visit in August as her mother is critically ill. It isn't possible to re-arrange her schedule for the remainder of this year but we are confident that she will be in Tasmania in July/August 2002. You can access a lot of Carol's innovative work by subscribing to the Jenison Public School's quarterly magazine, 'The Morning News', through Giant Steps Tasmania.

The National Biennial Conference – Sept 27th -29th 2001

Autism Tasmania has made funds available for 3 of our **personal members** to attend the conference. **WOULD YOU LIKE TO ATTEND?** Funding includes airfares to Adelaide, registration to the conference and 3 nights accommodation. If you would like to apply for this funding please write to Autism Tasmania, PO Box 1552, Launceston 7250 and tell us the reasons you would like to be at the conference. (Another flier regarding the program is in this newsletter.)

A personal membership is one which you or your family have paid for. It **DOES NOT** include memberships paid for by an organisation or employer which covers all those working for that organisation. Applications should be received in writing by the last mail of July 13th. The successful applicants will be notified by the end of July

Inaugural World Autism Congress.

Unity through Diversity

Work is continuing on the organisation of this congress to be held in Melbourne – November 10th – 14th 2002. To check details, visit the website which is now in operation. It is www.autismcongress.com

WHAT'S BEEN HAPPENING?

NEWS FROM YAST

(Supporting Families teaching Applied Behavioural Analysis)

D e a r R e a d e r ,
Autism Awareness Week is over for another year. It was terrific to see in the media a few dedicated stories, in particular a new family showing viewers how children can develop so wonderfully with early intensive behavioural intervention. Then there was Temple Grandin's story. If anyone is interested in that, they may contact YAST. Did you talk to someone about autism? It's a small yet often fruitful step to take. A simple "Did you know it's Autism Week?" may be all you need to say. Practice talking with your hairdresser, they always have an open ear. Voila! You're an advocate!

Since our inception members have consistently and persistently worked to raise awareness for our children's needs in the areas of diagnosis, therapy, education and the general community, eg training colleges and hospitals. This is demonstrated further by YAST's current involvement on working parties that are formulating programs to present to *SEAC* and so implement the recommendations from the review of the *Inclusion Policy*.

Over the past few months YAST has been supportive of a few active requests from members. This kind of feedback is terrific and assures committee that members feel their opinions are warranted and listened to. What's more, these issues can be raised in the relevant forums that YAST is representative on. Some of these requests involve therapy requirement, rebate for therapy and Individual Education Programs (IEPs). Some form of action on each of these issues has been initiated.

The year rolls on and in April we were pleased to hear Wendy Lawson speak to a large group of new and old acquaintances about her life and experiences. This time I came away excited to be more active in pointing out all manner of differences to our son. From our choice of morning drinks to rules for various times and places, then ultimately, sharing peoples' difficulties and skills. With this global approach to diversity, a child's awareness may grow and the gate gently opened for discussion about personal difficulties and skills.

Clinical psychologist, Jura Tender, will be in Tasmania again late in June. Diagnostic and/or therapy services and presentations may be booked through ISADD (Peta Kelty Ph 6265 9008 or YAST Rosemary Rush Ph 6229 5760). Early inquiries get preference.

The Petrusma-Reeves "Concert for a Cause" was held April 7th at the Wrest Point Casino. With over 1300 attendees rocking along to the Giant Hamsters and Patrick McMahon, the night was a winner, especially for YAST and former Miss Tasmania, Angela Potter. Our sincere thanks go to the organisers and Angela for her involvement and we pass on our encouragement for her continued success. As a result, YAST's resource library continues to grow and we have reading books along at every meeting.

By now I guess some will be nearly finished first term of school or perhaps already enjoying the slower paced mornings of the holidays. To those members who aren't at school yet, make the most of your time for therapy, it's important! Take Care,
 Rosemary Rush – Secretary

Calendar of YAST Events

20th June Anita Killick's
 12 Allambee Cres, Glebe

18th July Judy Stanfield's
 24 Laguna Pl, Goodwood Ph 6273 2676

15th August Grace & Chris Talbot's
 56 Hiern St, Blackmans Bay Ph 6229 7818

19th September Carolyn Geard's
 11 Jordan Downs Drive Brighton
 Ph 6268 1104

We aim to have books for members to borrow at every meeting. All our meetings have been well attended this year. Everyone is welcome from 7:00pm and meetings can finish at about


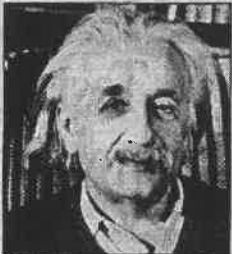
NEWS FROM GIANT STEPS

Autism Awareness Week brought a little excitement to Giant Steps. Monday, 14th May saw the opening of a retrospective exhibition of art works by the children of Giant Steps, past and present. Over thirty pieces were on display in the Meander Valley Council Gallery, including pieces owned by the Council and by parents, staff and friends of Giant Steps.

The Mayor of Meander Valley, Mr Greg Hall, who has just been elected as Member for Rowallan in the Legislative Council, opened the exhibition and launched Autism Awareness Week in the region. He spoke about the particular difficulties for parents of children with ASD, and about the lifelong problems which people with ASD face. He acknowledged the responsibility of governments to support these people and suggested further meetings with Giant Steps and Autism Tasmania to identify ways in which he could help. The exhibition will be on display until mid-June and is well-worth a visit. The Gallery is in the Service Centre, Lyell Street, Westbury, next to the old Council Chambers.

Thursday of that week saw Giant Steps undergo its regular review for registration. As an independent

AUTISM

Many experts believe that both Einstein and Mozart had Autism, but not everyone with Autism is a Mozart or an Einstein!

People with Autism have a great range of abilities and are found in every age range, socio-economic group and in every nationality.

There are people with Autism in your community, and perhaps within your family.

**Autism Awareness Week:
May 11th-19th.**

Appeared in The Examiner on Thursday 17th May 2001

school, which receives Government funding, Giant Steps has to fulfil rigorous requirements in respect of its premises, curriculum, policies and procedures. A great deal of documentation is provided to the Schools Registration Board, and a Review Panel appointed to visit the school for discussions. Their report goes back to the Board for consideration, so the outcome will not be known until August. However, members of the panel were complimentary and commented on the effectiveness of recent changes to our structure.

Following a very successful evening with Wendy Lawson in April, and to mark Autism Awareness Week, Giant Steps' staff and parents conducted a discussion on Communication, at St Michael's Association. At the time of writing, the evening had not yet been held, but we hope discussions of this kind will become regular features of our calendar and invite parents of children with ASD to contact us with suggestions for future programs. In its six years of existence, Giant Steps has developed an enviable level of expertise in many facets of Autism-specific education. We don't promote just one intervention but believe in the effectiveness of an eclectic approach, drawing on the best practice of schools in Australia and overseas. Every child is different and there is no magic cure. However, good and well-planned interventions can make a difference.

Unfortunately, Carol Gray has had to cancel her entire New Zealand and Australian visit in August due to her mother's ill health. Rescheduling for later this year is not possible, however, we are confident of bringing Carol to Tasmania at a similar time next year.

John Christie (Principal)

WENDY LAWSON VISIT.

Wendy again visited out state shortly after Easter. Her focus for this trip was to speak with as many organisations involved in the diagnosis and assessment field as possible. A great number of professionals took advantage of the subsidised rate to book Wendy to speak at their places of work. Those attending sessions in both the north, north-west and south of the state covered a wide range of service providers,

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which was extremely pleasing. Wendy had a very hectic schedule and really relished the challenge that this presented her. While in the state, she introduced a large number of people to her new book which was recently released during her trip to Britain. The book titled "Understanding and Working with the Spectrum of Autism" is a wonderful read. It is a combination of text-book with personal anecdotes included.

Those of you who read Wendy's first book "Life Behind Glass" will remember how readable it was and this new book is no exception. Autism Tasmania does have some copies of these books for sale. The prices are \$39 for "Understanding and Working with the Spectrum of Autism" and \$22 for "Life Behind Glass." Postage of \$3 applies if ordering by mail. You can place an order by writing to Autism Tasmania ,PO Box 1552. Launceston 7250. Wendy is very enthusiastic about returning to our state in the very near future and we may well see her before the end of the year. We will keep you posted.

Rose Clark



Some of the victorious Autism Tasmania trivia team

What Do You Mean We're On The Wrong Team?

The Autism Tasmania team enjoyed success at the recent Quiz Night run by the Devonport Rotaract Club. The \$1,000 prize was incidental to the satisfaction of beating the Giant Steps team! Strangely, many of the members of the two teams had links with both organisations. Our thanks to Clifford Craig Trust Executive Officer, Phil Baker for the accompanying photo. Unfortunately, team members are obscured almost in direct proportion to their contribution.

The powerhouse trio of Cheryl Scott, Grahame Knox and Brett Wedd secured the win with an outstanding quiz display; Helen Spinks, Mick Clark and Denise Thomson made solid, if slower contributions; but the most memorable moment came from Greg Spinks, who had been silent for most of the evening, other than a spectacular performance in the novelty horserace.

In the final double-points round, there was dead-silence to the question "What medical condition was Jimmy Carter treated for during his term as US President?" One voice spoke forward – "Hemorrhoids". The rest of us were incredulous but Greg was correct!

Clifford Craig Trust was 2nd and the Devonport Playhouse team 3rd. A great night and wonderful way to donate money to charity. Our thanks to everyone involved with Devonport Rotaract.

Mick Clark

AUTISM SUPPORT GROUPS IN YOUR REGION

AUTISM SOUTHERN SUPPORT GROUP
Contact Janet Smith on ph. 6259 1149

Autism Northern Support Group
Phone Rachel Hodge 63443261 for details

Autism North-West Support Group
Phone Rose Clark 6423 1086 for details

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



FEATURE ARTICLES

EYE CONTACT – A CONTROVERSIAL ISSUE

When and whether people with Autism Spectrum Disorder should be required to make eye contact is a controversial issue. The answer becomes more complex when you consider the individual differences of people with ASD. Some actively avoid it and become confused and anxious when it happens. Others may attempt it but later tell you that they were looking at the reflection in the other's person's eye or some other insignificant detail. Often recipients report the experience more as a stare or a gaze that looks right through you. It is rarely experienced as a communicative exchange. Some people with ASD learn to think about the social expectation around eye contact and make an effort to use it occasionally depending on the social context. When the individual is comfortable and feeling relatively competent, eye contact can be tolerated more easily. The same person in a confusing, complex or anxiety provoking situation may overtly avoid eye contact. Few people with autism, report that it ever becomes a really useful means for either receiving or sharing mutually understood messages.

In order to understand some of the controversy around this issue, we need to consider what the purposes are requiring eye contact and the assumptions that underlie them. Eye contact is seen as both an attention getter and a gauge to ongoing attention. The cue "look at me" is used to facilitate this response. It involves the assumption that when you have eye contact, you have attention and of course, those failing to conform to the request cannot be paying attention.

When a person with ASD fails to respond to the request "look at me", it is then often seen as non-compliance and can lead to a futile power struggle. Eye contact then becomes a goal to support compliance and following directions.

Some goals requiring eye contact assume that the individual with ASD has sufficient understanding of social conventions to make routine judgements about

where, when, and with whom eye contact is expected, as well as to spontaneously initiate and maintain eye contact in social situations. For example consider the goal "will increase eye contact when in social situations with peers. Students "will make eye contact X number of times every 10 minutes when involved in shared activities."

We need to consider if insisting on eye contact actually meets, or hinders, these hoped for outcomes and try to better understand the complexity of eye contact from the perspective of the individuals with ASD.

A number of "higher functioning" adults who have autism have described difficulties with making eye contact. One well educated man who has Asperger's Disorder, summarised his difficulties in this way; "If you insist that I make eye contact with you, when I am finished I'll be able to tell you how many millimetres your pupils changed while I looked into your eyes."

People who have ASD have difficulties attending to and interpreting even the most overt social cues in context. They have extraordinary difficulty with reading more subtle body language, including messages often conveyed by the eyes.

As well, some have great difficulty attending to two sources of sensory input at once. Insisting on eye contact may in fact mean that the

person is unable to attend to auditory information

Inconsistent individual response patterns also complicates the 'success' of eye contact as a target behaviour. There seems to be a natural inclination to assert that "if he could do it in that situation, I know he can do it in others" However, learning styles vary tremendously across tasks and each new task, even though it appears similar to us, is likely to be perceived as a new challenge to a person with ASD. There are many reasons why we simply cannot assume that because an individual with ASD did something a month ago, a week

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**Sometimes it's hard
being different**

Artwork from
www.autistics.org

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ago, or yesterday, he can do it today. This 'leap of faith' as opposed to better understanding the possible difficulties that the person may be having, too often characterises attitudes regarding individuals' abilities to make eye contact either spontaneously or 'on demand'.

Jean-Paul Bovee is a "high functioning" man who was diagnosed with autism at the age of three and a half. He describes his experience with eye contact.

"Eye contact is something I have always had trouble with. It does not come naturally to me and I do not appreciate having to give it all the time, especially to people that I do not know. All of the stress that is put on doing it makes me nervous, tense and scared. Doing it also assumes that I can read the message in another person's eyes. Don't count on it! I can look at a person's eyes and not be able to tell what they are saying to me..."

...as a child, my eye contact was worse than it is right now. People without autism could not understand why I would not look them in the eye...just because I am not making eye contact with you does not mean that I am not listening to you or paying attention to you. I can concentrate better not having to keep eye contact at the same time. I tell people you have a choice. Do you want a conversation or do you want eye contact? You will not get both unless I am comfortable with you and do not have to concentrate so much on the eye contact."

When developing strategies aimed at focusing and maintaining attention on the part of individuals with ASD, we need to recognise that conventional social expectations may in fact interfere with learning. Guiding individuals in focussing and engaging in tasks specifically related to the activity at hand is often more effective than trying to obtain attention through eye contact and then expecting that person to quickly shift attention to a set of task related stimuli.

Eye contact is a very social, almost intimate type of interaction. When, whether, and why to insist that individuals engage in that exchange are questions that require ongoing scrutiny, understanding and flexibility

on the part of people who interact with individuals who experience challenges common to autism spectrum disorder.

The insistence of eye contact for people with ASD may still remain a controversial issue for some. However, it is clear that the need to define the purpose we wish to achieve through our instructions and expectations, as well as the need to assess, through individual's response, if those purposes are being met, remains clear.

Adapted from "Should We Insist on Eye Contact with People Who Have Autism Spectrum Disorder?" from Indiana Resource Centre for Autism Reporter, Spring 2000, Vol 5, no3


Reference Bovee JP (199) My experience with autism and how it related to "Theory of Mind"- Part 1. Advocate 32 (5) 18-19

Reprinted from Keynotes Autism The Newsletter of the Association of NSW Dec 2000

How does Autism Affect People?


Autism is a lifelong condition that affects the way in which an individual

- Communicates with others
- Socialises with people
- Learns about his/her world



Be Autism Aware

For more information contact
Autism Tasmania
PO Box 1552. Ph/Fax 6423 1086
Launceston



Appeared in The Examiner, The Mercury and The Advocate on Friday 18th May 2001

A CHATROOM FOR AUTISTIC KIDS by Kis Brink Submitted by Geraldine Robinson

This is an article by my Canadian friend, Kis Brink. She runs a chat room for children on the spectrum and siblings. I am one of the ops who looks out for predators and helps the children chat. It would be great to have some Tasmanian children there too.
Geraldine Robertson

Autism and Asperger's Syndrome create isolation and loneliness that it is hard for people who live without these conditions to understand. Often instead people see those of us on the autistic spectrum as unfriendly and aloof. We don't do things or see things in the manner people expect so conclusions are reached about our seeming withdrawal from the world. Many people decide we really don't want to be reached or have friends. Some even think that we are in fact incapable of basic human abilities that facilitate the process of socialisation.

In the process of studying for my psychology degree for one paper I plowed through 50 years worth of attempts by experts to teach children with autism how to play. Cars should be pushed on the ground not held upside down while you spin the wheels. Just that one simple thing, the correct way to play with a car, had been written up so scientifically and seriously for decades. It boggled my mind the amount of time and effort that people were willing to put into this believing that appropriate toy use would lead to other social behaviours. Basically the experts all seemed to agree that we didn't play correctly, some were reluctant to call it play at all. We had no imagination again partially because of observed play behaviour. They see a child doing the same thing over and over and conclude this is the result of a lack of imagination and "stereotyped and restricted patterns of interest" accord-

ing to the DSM-IV. My kindergarten teacher felt I needed another year of kindergarten since I "didn't even know how to play right." So you are five years old and you are basically flunking the thing that kids are supposed to do.

To me the other children made no sense at all. I thought I had finally arrived at school. Where I would be able to show I could read and not read covertly because I felt like I was breaking some rule by knowing how, too young. People on the autistic spectrum often have sensory hyper-sensitivities, so the sound of your 19 classmates, who can play properly, actually playing is enough to make you want to run and hide. The sound of markers on paper or the way the low quality painting paper feels if you accidentally touch it are all excruciating. These things just do not occur to people who have normal nervous systems, as being potential barriers to all this play that we are supposed to be doing.

Kids can be cruel. People say it over and over. I don't think they mean to be. They just reach their own conclusions based on what they know of the world and what they hear adults saying. In my class there was a boy with Down's Syndrome. What the children saw was that he could play in all the required kindergarten ways and I could not. To them the other "retard" could play so I must be an even worse "retard". What do you do then? You are a month into school - a place you had envisioned as a wonderful place where you would read and learn - and instead you are humiliated and ostracised.

I thought something was wrong with my teacher at first because she wasn't teaching us anything.

She read to us. It was clear that we were not supposed to read to ourselves. She moved us around from one plaything to the next and despite all of what I considered needless activity in a school, we even had free time where we were allowed - in theory - to do what we wanted. In theory, because if you used that time to scuttle back to the reading corner and try to find a real book with actual words, you were quickly questioned as to why you were not playing. Kids with forms of autism have their own perspective on the world. Unfortunately those who are non-verbal cannot share it and those who are verbal often choose not to or try to in a way that makes no sense to the listener. So I never asked why we were not reading and writing

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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.

and learning math. I thought the teacher allowing all that running around and yelling was totally scandalous and even if she got caught that she would be in trouble. Of course that never happened. Instead you learn you are the problem. -the one kid in the whole class who isn't on the right track.

Higher functioning forms of autism were poorly understood back then. If you learned to talk, your parents and everyone around you would either conclude that you never had it or you had outgrown it. So everyone expects you to just get with the program and play right and talk more and make friends. Everything would be okay if you could just do those things and your lack of compliance at these things would be given any variety of names. You were asocial, stubborn, and non-cooperative.

You would probably never have friends at that rate and you knew this was important. I comforted myself with the belief that I must be from outer space as there were clearly none of my kind around. When I started chatting with other adult autistics online, I learned that the alien theme was actually pretty common.

Things are better understood now. Autism in all its forms is permanent. The brain is neurologically different and always will be. They have realized that many of the problem behaviours have routes in sensory problems, which can be addressed. There is no cure for autism, but there are treatments. But it remains a lonely thing to have. So how is that addressed?

Well for myself - and many others like me, we discover computers and - even better, we discover that there are places to go to meet people like ourselves. You go into a chatroom just for people on the autistic spectrum and suddenly you are home. They don't care if you hardly chat. They actually understand how you see things. Suddenly people are relating to you as you and not whatever you have learned to do; to make yourself less offensive to the world.

It occurred to several of us at the same time that children with autism and Asperger's could benefit from this same sense of belonging. A chatroom was born for kids on the autistic spectrum and their siblings. I run that little corner of cyberspace. I sometimes feel like it is the slowest corner. We have to keep the chatroom private so people surfing the net don't come in. Word

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gets out slowly on web pages and when parents are on the autism channel the kids start to come. Now this may seem like no big deal to a lot of people - modern kids chat and surf the web. But to kids with autism, computers link them with a whole new thing. They will meet other children like themselves. They will see adults who have survived whatever age they are going through. They know in a way that persons my age didn't that they are not alone.

Facilitating computer-chat for kids with autism is a little different than in other kids chat rooms. Kids on the spectrum can obsess on one theme forever. It immediately became apparent that I was going to have to learn more about Pokemon. Well, sure you say, all kids are obsessed by them, but it is the degree and extent that surprises you. My nephew asked me this Christmas if I knew that Pokemon were no longer cool. I told him they were with the kids I knew. Parents express frustration that there kids will perseverate on one theme forever getting left behind when other kids move on to the next cool thing. Not in our room - Perseveration is supposed to be one of the negative parts of autism. I pointed out today when someone was worrying about this; that if two kids perseverate on the same thing a conversation happens. The Pokemon obsession gave me a place to start with kids who I never meet in person who are sent to the chatroom by someone who thinks it will be good for them. I sometimes know the parents and therefore a bit about the child but often I do not. So this particular craze was actually a blessing. Before the chatroom, I disliked Pokemon about as much as any adult. Though the kids in this household were way to into it and the fact that the fastest way to compliance was no more Pokemon was a little alarming.

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Autism Tasmania Information Kit

\$12.00 includes postage for Parents

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To the kids of the channel though Pokemon like the computer were a sort of tool. Something to build a bridge with. I had to buy myself a Game Boy and a Pokemon game to be respected and trusted. Suddenly I was cool. Granted I was cool with a very small group, but the night every single kid had a Pokemon nickname and were pleading with me to change my nickname to Ash so I could be their trainer stands out. In that room the kids socialize. They demonstrate imagination by coming up with Pokemon scenarios. They make jokes. All these things are supposed to be very difficult for them. Most of them cannot do these things in person. Being that one step removed by computer makes it easier somehow.

Over a year has passed since this special place came into being. Some days are so slow I wonder why I am spending so much of my time waiting for kids to come. Some days I get frustrated because six kids come in, but they come in one at a time. Most of them don't mind that they wind up talking to an adult. In fact it is often easier for them - but nothing makes me happier than when they interact with each other. Today was memorable. A sibling came in. His mom wanted him to try it. We talked about hockey and sports. Then by chance someone came into the autism room asking on behalf of a child if anyone had Asperger's. I said I did and in fact there was a place especially for kids on the autistic spectrum and their siblings. This was apparently great news and I was promptly labelled terrific. A label I have to confess I like a lot better than asocial.

Children on the autistic spectrum often have motor problems and poor muscle tone so I was a little worried about how what we had been talking about was going to go over with the child with Asperger's. Fortunately she liked sports too. A big relief for me - as quickly the kids were talking to each other and while I

occasionally contributed a comment or replied when a question was addressed to me, the kids were doing most of the talking to each other. Could we be friends was a question. I said without too much thought that we were there for that. I tried to sort out the time zone differences as the kids worked on how they could get together again. The mums took over long enough to arrange a cyber play date. The kids had homework and bed to attend to and they were gone. A pretty good day for the room I thought.

Then back in the autism room the person who had come in on behalf of the child reported to me that the child with Asperger's was so happy that she had raced out to say words that parents of kids on the spectrum long to hear. "I made a friend" -four words that signal a whole new era for a child with Asperger's. Having made one friend, suddenly this seemingly impossible thing that they were beginning to suspect might never happen, had happened. Having happened, you are no longer a kid who has never had a friend. It could happen again- A whole new branch of possibilities. A parent of a child not on the autistic spectrum might be tempted to say it isn't a real friend. My brother says the same thing about my cyber-friends.

But parents who think they might never hear those words are not going to say to their child that friend doesn't really count because they live in another country and time zone. A friend is someone who accepts you and likes you as you are and that's the miracle that computers have brought into this generation of kids with autism. They will know that their are kids like them, that there are kids not exactly like them - but who accept them for who they are, and that there are older people who have many of the same problems, but have lived through many of the things they deal with.

So, when people wonder why I and others like me spend time with these kids scattered throughout the world, it really does boil down to the beauty and joy of hearing a child with autism or Asperger's being able to say that they have a friend - and the hope that they will have better lives for having discovered this earlier in life than the pre-computer generation of kids could.

Kis Brink

The following article had a critical typographic error in our last edition. The entire article has been reproduced and the corrected sentence highlighted. Our apologies for any confusion brought about by this error.

WRITING SOCIAL STORIES

Many readers of Autism News will know of Carol Gray, who was a keynote speaker at the 1999 National Autism Conference in Hobart. Carol, Director of The Carol Gray Centre for Social Learning and Understanding, developed the concept of social stories to enhance social understanding in children who have an Autism Spectrum Disorder.

Last October, in Melbourne, she presented a two day workshop entitled FROM BOTH SIDES NOW – How to teach social understanding. A number of staff from Giant Steps participated, as did two parents, Penny Cromarty and Ros Ward.

Carol Gray is a most captivating speaker, who used personal experiences and anecdotes, often humorous, to illustrate all aspects of the workshop. The aim was to teach us how to write some basic social stories.

Carol took pains to describe the rationale behind writing social stories, emphasising that any social interaction (and therefore social understanding) involving a person with ASD requires at least two people, ie. the person with ASD and at least one other. Carol asserts that the social impairment is shared, that the non-autistic person is part of the problem associated with social understanding, and therefore needs to be part of the solution.

She urged us to think about our own social ability, and to consider the non-verbal and other “hidden” clues that “neurotypical” people use to get the gist of a situation.

Carol explained that the goal of a social story is to teach social understanding. It addresses the needs of people on both sides of the social equation. While the primary aim of a social story is not to change the behaviour of the recipient of the story, often an unsatisfactory behaviour changed

for the better, because as a result of a successful social story, a person may have greater social understanding.

Carol then got down to the nitty-gritty of writing the social stories. She stressed the importance of using positive language, and of clearly stating desired responses. Carol explained that social stories are composed of a particular blend of descriptive, perspective, affirmative and directive sentences. The workshop participants had opportunities to practice these and to read them aloud, for which Carol insisted they receive applause. **She talked about the need for literal accuracy and explained the basic social story ratio of 0-1 directive sentences for every 2-5 descriptive, perspective or affirmative sentences.**

Carol emphasized the need to use concrete examples to understand text, enhanced by appropriate visual supports. In fact, she said “if the child can’t see it, then you haven’t said it”.

She also stressed that social stories use text and illustrations that reflect an understanding of the reader’s cognitive ability, reading skills and attention span.

There was plenty of opportunity for us to improve on some poorly written stories that Carol presented. Getting them just right was, in fact, much trickier than we had realized, but Carol told us that when we had written 500-600, then they would come quite easily!

Based on information and references from Carol Gray’s workshop, Ros Ward and Penny Cromarty presented two sessions at Giant Steps. called *Enhancing Social Understanding- An Introduction to Social Stories*, Ros and Penny spoke to a group of parents and then to a group of staff about several aspects of Carol Gray’s workshop and both groups have started to write some basic social stories.

Penny Cromarty

BOOK REVIEWS

Autism Platform reviews: *Understanding and Working With the Spectrum of Autism-An Insider's View by Wendy Lawson*

Autism Platform members comprise: more able adults on the autism spectrum - two of whom are undertaking tertiary studies, a parent with Asperger Syndrome whose child is also on the spectrum; other parents - one of whom works at managerial level for a pharmacological company another who works in the area of disability.

Autism Platform members were privileged to meet recently with Wendy Lawson who invited the group to give an honest assessment of her book.

For those less familiar with the Autism Spectrum or unaccustomed to the language Wendy uses to describe the autistic world, her introduction and early chapters give succinct explanations which are simple and easily understood.

The entire book contains a plethora of references from eminent authors and up-to-the-minute research information; the group considering it an excellent reference for tertiary students of developmental disability and an ideal first year text for students of psychology. It was considered also to be of enormous value to anyone working with individuals having an autism spectrum disorder and particularly those individuals who are at the more able end of the continuum.

Mr Hatters from Launceston's specialist job agency, Intowork remarked that Wendy Lawson's book would be invaluable to those working in the field.

He suggested that whilst some of the 'handle with skill' strategies proposed in part three of the book were logical, common sense approaches he welcomed these reminders, saying that, it would have been useful to see these illustrated diagrammatically which one could photocopy and enlarge for display purposes. Mr Hatters applauded the innovative use of the 'key concepts' displayed at the end of each chapter.

The group went on to suggest that the book, however, should not be dismissed by those who do not have a professional interest. Wendy uses many case study examples to explain different cognitive styles and to illustrate the potential for misunderstanding between neuro-typicals and those with ASD. Parents reported an improvement in their understanding of such things as theory of mind concept and stress precursors saying also, that the autobiographical references and poetry made this reference distinctly different. It enabled them to draw analogies and to celebrate their adult children's' differentness and feel more hopeful about the future.

Those with autism read more slowly, each identifying with the writer if not always sharing similarities but in awe of her achievements, not least of which her ability to convey so much, so eloquently using a number of vehicles.

One Platform member with Asperger Syndrome said that she thought it was useful to see a copy of one of Wendy's school reports because it illustrated so well the false impression one could gain by such a report and the lack of understanding by teachers at that time regarding ' what made Wendy different'.

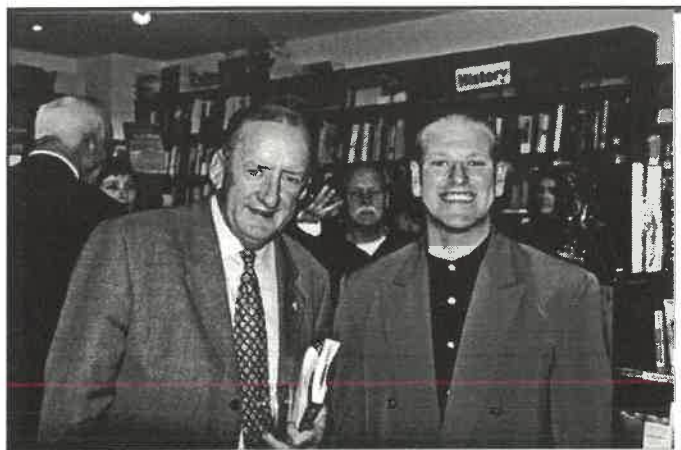
In conclusion this is a book for everyone, professional, student, field worker, work-mate, parent, neighbour – all delightfully summed up with a remark from a young adult man with autism: "There's no excuse for anyone now, not knowing or not understanding, is there Mum?"

submitted by Paula Barnes



"Autism isn't just about limitations. It's about seeing the small things, about extraordinary abilities, about seeing the world from an original perspective, about thinking beyond the shackles of words"

from autistics.org



Tim Fischer with Dane Waites at the book launch.

“SMILING AT SHADOWS” by Junee Waites

Junee Waites a long-time member of Autism Victoria has written an exceptional story about parenting a child with an Autism Spectrum Disorder. This book shares her experiences “warts and all” and shows the strength this remarkable woman has as a parent which also involved lobbying so that people would listen and understand.

FROM SMILING AT SHADOWS.....

‘As a two year-old Dane remained totally insular. He smiled at the movement of leaves and clouds and, once, into the lens of a stranger’s camera. On some occasions he smiled for reasons we didn’t understand. But he still wouldn’t smile for his mum and dad, and that almost broke our hearts.’

‘Dane began attending the Warrawong Day Care Kindergarten shortly after his fourth birthday. Despite everyone’s best efforts, Dane wouldn’t socialise at Warrawong, always hanging back unless a teacher physically brought him into the group.’

‘Dane had been at Warrawong for six months when a visiting psychologist, Pat Leivers, handed me a book. ‘You’d be interested to read this, Junee,’ she said. We read page after page, almost forgetting to breathe. Occasionally we’d pause and

gasp with astonishment. Here were our answers! Here was our son, right there in black and white on each and every page of *‘Autistic Children – A Guide for Parents’* by Lorna Wing.’

‘Establishing eye contact was the first and most important task Irabina set for Dane. It was twelve months before Dane could look us in the eye without becoming agitated. And we had to continue to work hard to sustain this eye contact. Then, for many years we’d need to remind him with the phrase, *‘Looking Dane!’*’

‘Dane had grown tall now, and his older appearance attracted stronger disapproval when he’d throw a toddler-style tantrum in public. One day, following such an outburst in a supermarket, a shopper tapped me on the shoulder and said, ‘Give him a sharp smack! That’ll fix him.’ The intensity of my angry retort surprised me: ‘I know what my son’s problem is. Other than being a busybody, what’s your problem?’ I was overwhelmed by incidents like this – added to which was the fear of never knowing when Dane would soil his pants in public. The sheer physical strain of going out became too daunting.’

‘Dane’s repetitive speech, or echolalia, was confusing to Rod and me, so I cannot imagine how astonishing it must have been to those new to the world of autism.’

When a teenager role-play helped to draw Dane into society. He’d always been on the fringe. He didn’t understand his role within the family or the neighbourhood or school. Now role-play helped him to understand how he fitted into these areas and to answer questions like *Who am I?* and *Where do I belong?*

‘One evening, just before his fifteenth birthday, Dane and I were watching a glorious rainbow arching over the Melbourne skyline.

‘What’s a rainbow, Mum?’ he asked me. I couldn’t bring myself to explain all that business of refracted light, so I said, ‘Well, Dane, I believe rainbows are God’s way of saying he loves us. We

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stood quietly together, watching the rainbow. The my son turned towards me and looked deeply into my eyes. 'I love you, too Mum!' he said. For the first time in his life, I knew my son really did love me.'

ENDORSEMENTS FOR SMILING AT SHADOWS.

"Smiling at Shadows is a remarkable book. It is an insightful and honest account of the often difficult path to adulthood that a child who is 'on the spectrum (of autism)' must face. But most importantly, for the general community, it reveals something of the heartache and of the joy that comes with living with autism." **Judy Brewer Fischer and Tim Fischer.**

"Books about troubled or chronically ill children are fraught with literary pitfalls and seldom work. Here then is that brilliant exception. I urge you to read this funny, sad and beautifully written story." **Bryce Courtenay**

As both a professional and a parent in the field of autism, I found this book deeply interesting and moving. The account of Dane's life from birth onwards explains, much better than any scientific treatise, the strange ways of perceiving the work that arise from the unusual pattern of brain development underlying autism. The bewilderment, pain and self-doubt experienced by Danes's parents in his early years, Junee and Rod's slow journey

Deadline 17th August

*The deadline for the September issue of Autism Tasmania will be **17th August***
Please forward your copy to Cheryl Scott
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A big thank you to everyone who helped me get this issue out ON TARGET – it was greatly appreciated! Cheryl – Ed

towards understanding and Dane's eventual remarkable progress make an absorbing story. Even parents, who, like myself, have children whose autism is so severe that they will make only limited improvements, will find the insights into the world of autism, as explained by Dane, of real practical help. Professionals in the field who read it will learn a great deal. For those who are not involved with autism in anyway, this book offers a fascinating insight into a different world. **Lorna Wing MD**

NOTE: *Autism Tasmania was sent a copy of this book by the publishers Harper and Collins. The author Junee Waites also sent an invitation to the book launch which was in Melbourne on the Tuesday following Easter. The committee of Autism Tasmania sent Junee, Dane and Rod flowers to celebrate the occasion. Shortly after the book launch in Melbourne, we received a photo of the Waites family with the flowers sent by Autism Tasmania. The complimentary copy of "Smiling at Shadows" will be included in the library of Autism Tasmania for our members to read. (I have read this book and found it extremely compelling and "un-put-downable." – Rose)*



*Dane, Junie and Rod Waites
with the flowers from Autism Tas*