



Welcome to the Christmas Issue

Welcome to the December edition of Autism News. It has been a very busy three months as we have enjoyed visits from Deanne Michaels who presented two workshops in Launceston, and one on the East Coast, and also from Wendy Lawson who spoke in Devonport. One of our members, Mary Brake took her family to listen to Wendy, and has written for this newsletter, a wonderful account of the presentation, and its meaning to them. We also had a booth at the Childrens' Expo run by Anglicare in Launceston in November, and Rose Clark and Ros Ward spent the day talking to young parents about Autism Spectrum Disorder.

The committee has just completed an investigation into how Autism Tas can best support its members. This was funded by a grant from the Tasmanian Community Fund and Mick Clark has written an article for this edition about its implications. We do not receive any government funding so it is a continual challenge to find ways to fund the position of Family Support Coordinator.

2007 promises to be an interesting year, with a national biennial conference, called Creative Futures, on the Gold Coast in March. Autism Tasmania will continue this theme with a one day conference in Hobart in Autumn. An Art Exhibition for people who have an Autism Spectrum Disorder is also planned.

The Family support Coordinator, Rose Clark, will take some well-earned annual leave in the next few weeks. Thank you, Rose, for your work this year.

There are some new contact details for Autism Tas. Our website is now running much more smoothly, and we have a new phone number, 6362 4755 for general and library enquiries at our office at Giant Steps at Deloraine. The contact details for Rose Clark remain the same.

The AGM for Autism Tasmania was held in September, and this newsletter contains some information about the voluntary committee that runs the organization. I welcome our new committee member, Carolyn Moore, and thank all the members, particularly the immediate past president, Ros Ward, for their contribution over the last year.

We have included an article from Western Australia, entitled " Putting the Happy back into Christmas " . For many families who have a member with an Autism Spectrum Disorder, this is a really stressful time of the year as routines are disrupted, unfamiliar events such as excursions and parties take place, and the prospect of the weeks of unstructured time loom ahead. This article may provide some strategies for managing these.

For others, the Christmas break may provide a welcome break from a difficult situation at school.

I wish all members of Autism Tasmania a Happy Christmas and a wonderful new year.

Penny Cromarty.

Putting the 'Happy' into Christmas

reprinted from *Autism News WA Dec 2006* Autism Association of Western Australia

When we consider the core features of autism, we can see that many of the things that non-autistic people enjoy about the holiday season have the potential to cause difficulties for our children and adults with autism. For many people without autism the lead up to Christmas and the festivities with gift giving amongst family and friends provides a welcome and joyful relief from routines that govern their day-to-day lives. But, for individuals with autism, the loss of those routines, the social expectations and all of the sights and sounds and smells associated with the festivities could be confusing and overwhelming. A diagnosis of autism means that the person has specific impairment in communication and social understanding, and also in imagination, with limited interests and stereotyped behaviours. These core deficits, along with their sensory difficulties, can lead to difficulties with holiday celebrations unless we take steps to reduce their impact or provide supports. In this article we look at some ways we can help the whole family to enjoy the holiday season.

Preparing for change

Routines and rituals can play an all important part in maintaining a sense of order and calm in the person's life. Because we understand the nature of autism we make adjustments all the time to enable the child or adult in our care to function as independently, efficiently and comfortably as possible. The routines that we help the person to establish, become integral to their independence, efficiency and general ease of functioning. So how will we compensate when those routines break down during times of major change, such as the Christmas period? Whether the individual in our care is a young child or mature adult, and whatever their level of ability in communication, it is important that we prepare them for the fact that their routine is going to change and give them some idea of what will happen. Of course, exactly how we do this and what kind of information we provide will depend very much on the person and their family. For the older person with good language skills we may focus more on putting social events on the family calendar and helping them to plan how they can work around any difficulties they might encounter. For the younger or less able person, we might provide a much higher level of structure and lots of visual supports letting them know just what will be

happening. Of course, visual cues should not be disregarded just because the person has good verbal skills. In this case it could be helpful to mark off the calendar, day by day, to enable them to see the passage of time up to the end of school term, or to breakup from work, or to Christmas day. For the individual with fewer communication skills the approach to Christmas could be shown using Compic or other pictures indicating the number of sleeps to the big day.

Decorations

Decorations in the house, in the shops, etc help to make Christmas special and add to our enjoyment. However, for some people with autism this is not true. For some people with autism, the whole process of bringing in a tree and putting up decorations everywhere is very disturbing, because it changes the appearance of their familiar environment. Rather than being exciting, these changes can make people feel anxious and fearful. Home is a haven for all of us: it's where we feel most safe. The world can be overwhelming for the person with autism. Having a safe place is even more important for them. Thus we need to consider the impact of making grand changes to their home. What we regard as festive could be frightening through the eyes of autism. If this is the case, it is important to recognize it and help the person to cope. This does not mean that you can't have decorations, but it may mean that you need to make some compromises. The first obvious compromise is to realize that the whole house does not have to change. If the family member with autism relies on having the environment remain familiar, it may be preferable to leave parts of the house untouched, so that they can feel safe. You can still have a beautiful Christmas tree with lots of decorations etc. But if the person is upset by changes to the environment, it can be helpful to set limits on those changes so that the person with autism doesn't feel overwhelmed. Of course we also need to inform the person about what we are doing. If the rituals of your holiday include decorating a Christmas tree and putting up decorations throughout the house, this could be indicated on a count-down calendar showing the day on which we are going to put up the tree and, importantly, when things are going to go back to normal. (A word of warning regarding some

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Christmas items on sale: they're not always safe in the hands of everyone, especially if they look tempting enough to go in the mouth!) Including the person with autism in decorating the house can also provide a lot of fun for some, as well as making the changes easier to cope with. However, if the person does not want to be involved, remember, holidays are meant to be fun, not a chore.

Giving and receiving gifts

The social skills deficit intrinsic to autism is a specific deficit, not just a lack of social skills that might arise from lack of education, or social opportunity. People with autism have a specific impairment of "theory of mind" which means that the person with autism is impaired in their ability to understand the thoughts, feelings and intentions of others. (See May 2003 issue for more information on "theory of mind"). This means that, while the person with autism may have been taught some appropriate responses, such as saying thank you for a gift, or may have a limited understanding, they do not have that intuitive understanding of the giver's perspective to guide their response. Most of us, for example, can still respond positively to gifts that we don't particularly like because we appreciate the good will that prompted the giving. But the specific impairment of autism means that this understanding does not automatically guide the responses of the individual. Unfortunately, this can lead to inappropriate responses and hurt feelings, for example when someone receives a gift, says a mechanical thankyou and then tosses it aside to play with an empty box. Of course, we often see this kind of behaviour with very young children, but with them we accept it because we understand that it comes from their lack of social maturity and that it is not intended to be rude. With older people, we often mistakenly think they are being deliberately rude or hurtful. Thus, it might be helpful to explain to visitors and extended family that the person with autism is not being intentionally rude by the lack of positive response to the gift that he or she has just been given. Depending on the age and ability of the individual, we may also use social stories, role plays, etc to help the person with autism understand the feelings of the gift giver and/or how they should respond to gifts. (For more information about social stories visit the website www.thegraycenter.org).

Keeping cool at party time

Special clothes, lots of friends, dancing to loud music, playing run-around games, lots of fancy food and drinks etc may be heaven for many young and not so young party goers. But for those with autism it could be quite the opposite. Almost every aspect of a typical party that other people may find enjoyable; the noise, the crowd etc, could be quite distressing for the person with autism because of their sensory issues. Of course, we want the person in our care to be included as much as possible in gatherings of family and friends, but sometimes the crowded party scene is simply not a place where they will be comfortable and we might need to consider alternatives. Although everyone with autism will share core features of the disorder, tolerance levels with regard to environmental factors (as in the party scene described) can vary greatly. Some young people with autism simply love the disco/party environment (although we might need to ensure that they don't become over "high"). For some, toleration of noisy environments can be greatly enhanced if they are provided with ear plugs or ear muffs. Even the type of ear pieces associated with a Walkman can provide some noise protection; and they look sufficiently cool for a bunch of teenagers. It's always a good idea to ensure that an escape avenue is available for the person if it all becomes too much for them: a quiet place where they can go with favourite comfort objects, just to remain calm. Others may be able to enjoy the party if they can take breaks in a quieter environment every so often or if they are not expected to stay for too long. Making some simple plans, and rehearsing coping strategies with the individual, can make all the difference between an enjoyable and an unpleasant experience for the whole family.

Dress for comfort

We all have our favourite items of clothing, some of which can acquire the status of "comfort objects" for many of us. Because of their sensory sensitivities and their difficulties with change, this is particularly true of people with autism. Many people with autism find that clothing with the wrong characteristics can cause real difficulties. For example, Temple Grandin has described her experiences having to wear "special" clothes, not simply as uncomfortable, but as extremely painful. Therefore, unless you are very confident about the reaction of the person in your care, it's probably not a good idea to plan on new clothes for them, for a special

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event. For some people with autism the newness of clothing will not present a problem but for many, with sensitivity pertaining to touch, new fabric against the skin could be truly painful. For others, the rejection of new garments might be more to do with the comforting habit of the old, rather than sensory sensitivity. In either case, since parties are challenging environments for the people with autism, it seems wise not to add the extra challenge of unfamiliar clothes.

Festive food v. favourite food

The special food that is presented at any celebration meal may not be appreciated by the person with autism if it is different from their usual fare or doesn't fall within their limited diet. If necessary pack a lunch box of acceptable food when dining out. This is not "indulgence" or "spoiling" the person, it is simply

acknowledging that in many areas of their life there are limitations, and that we need to work around those limits. Fortunately, family and friends are usually understanding of the special needs of the person with autism.

Christmas for everyone

By maintaining some of the everyday routines and rituals during the days of Christmas we're working towards enabling the person with autism to enjoy the festive period. Christmas festivities at home, school, the work place and in the wider community, make this a period quite different to any other time of the year. We need to prepare our people with special needs for the changes. To ensure that everyone has an enjoyable time we must keep in mind the changed environment and atmosphere that Christmas brings and make the appropriate accommodations.

Mean what you say and say what you mean.

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One of the communication and language difficulties for a person with Autism Spectrum Disorder is that of interpreting language literally. A person with autism can interpret the words said by others in terms of their precise meaning, rather than the meaning the whole saying has when used in everyday language. Australians use a lot of colloquialisms and slang, and this can make things confusing for a person with autism. Kirsty Kerr, the Autism Victoria Family Counsellor, has written this article to help everyone navigate the complexities of language.

Temple Grandin, a well-known adult with Autism Spectrum Disorder, talks about thinking in pictures'; her thought processes characterised by visual images'. When we use language including a noun, such as 'ball' to mean something other than the object ball, such as in the saying 'she was on the ball', we can confuse the person with Autism Spectrum Disorder. The person may picture a ball, wonder where the ball being referred to is, and grapple with how that ball relates to what was previously being talked about.

A teenager with Autism Spectrum Disorder once asked "What does 'send my regards' mean?" Because the word "regards" has no tangible physical form or visible action, he was unsure about what he was supposed to send. Similarly, a young boy with autism clearly struggling to put some Lego pieces together was asked

"Do you need a hand?", to which he answered "No".

When the question was rephrased to "Do you need help?" he immediately handed over the pieces and said "yes". Logically, in response to the first question, he decided that as he already had two hands he certainly didn't need another one. However, he did need help.

The following article covers some phrases that may pose a difficulty for the person with autism. Many of the examples, in addition to those above, have been shared with the Family Counsellor by individuals caring for a person with autism. The real life examples illustrate the confusion faced by individuals with an Autism Spectrum Disorder when we don't say what we mean.

School staff or carers

At school, the class teacher may use group instructions that are misunderstood, and the child therefore is unable to follow what the rest of the class is doing. Take for example the instructions "class, sit down" or "everybody line up at the door". As the child's name is not used, they may not understand that this instruction is for them. The child should be explicitly taught that the collective terms 'class', 'everyone', 'guys',

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'everybody', 'boys and girls', etc. include them too.

When improvement is required, a teacher may use the terms "pull your socks up", "get with the program", "lift your game", or "get on with it" when what is really meant is "I want you to try harder". The clearest way to express this would be to tell the child exactly what behaviour you expect, for example by saying "Complete the last two questions on the worksheet". Similarly, when a teacher wants the class to finish an activity, they may say "let's call it a day", "wrap it up now", or "it's time to call it quits". It is clearer to say, for example "Stop writing now and put pens away"

Here are some more examples of what is said, what the Autism Spectrum Disorder interpretation is and what was meant — and therefore should have been said!

Person says:	What is 'heard':	What is meant:
'I'd like a word with you'	After the person has said a single word, I can stop listening	'I want to talk to you', or 'Please listen carefully'
'Hold your horses'	Where are the horses?	'Please wait', 'stop moving', or 'stand still'
'Get your skates on'	But I don't have any skates.	'Please hurry' or 'Try to work faster'
'In a minute'	I only have to wait 60 seconds	'First I will finish ____, then I will help you'

Some children may not be just confused by some phrases, but actually fearful or anxious. When the misbehaving child is told "I'm going to keep an eye on you." they may become frightened that the other person's eyeball will be literally touching them. It is better to say, "I'm watching to make sure you don't do ____ again."

Consider the following real life example of a 4-year-old boy at kinder. The kinder were to have a parade and concert with the theme of 'Possum Magic'. The teacher was preparing the children for a rehearsal, and "OK children, it's time to turn you all into possums." While the rest of the class went to find their masks, this particular boy screamed with fear and ran away.

Similarly, a primary school student spent an evening of anxiety not knowing how to proceed with his homework, as the teacher had said "You can finish colouring the picture at home, if you like". His parents eventually relieved his anxiety by explaining "if you like." means he could choose to colour the picture in, or choose not to colour it in.

Classmates

Other students, particularly teenagers may use slang, such as "I roll into class whenever I feel like it." which is confusing to the person with an Autism Spectrum Disorder. "When someone brags "I could do that with my eyes closed. (or my hands behind my back)", what needs to be said in order for the person with Autism Spectrum Disorder to understand is "that's easy, I'll have no problems in finishing it".

When a classmate says "What's on the cards this weekend?", what they should say is "What will you be doing on Saturday?". Imagine what connotations the phrase "The teacher bit my head off" has for the person picturing the scenario literally. Consider the following sayings, and what is meant.

Person says:	What is 'heard':	What is meant:
'I changed my mind'	The person took out their brain and swapped it for another one	'I want to do ____ instead now'.
'Are you right?'	To the right of what?	'Do you need help?'
'He took the bait'	Where are the worms?	'I fooled him' or 'I tricked him'

Misunderstandings at home

Many parents can become infuriated that they ask their child repeatedly to complete a task, only to be met with inaction. If they asked their child "Can you put the dishes away?" the child might interpret this literally as "Are you capable of putting the dishes away?" to which they may then answer "yes". The parent thinks the child has shown their intention to do the task, the child thinks they have answered their parent's query, and therefore that's the end of the response. In order to avoid confusion, phrase your request as a statement; "Put the dishes away, please", rather than a question.

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“Put the dishes away, please”, rather than a question.

When parents are reprimanding children for being ungrateful, they may say “I bend over backwards for you, and you don’t appreciate it”. Whilst the child is picturing the parent doing acrobatics, they are missing the point of the lecture. Try telling the child exactly what you want them to do, such as “Say thankyou after I give you a treat?”

Out in the community

A carer in an adult service told her client “Take this tablet and the pain will go”, to which he replied “Go where? Where will the pain go?”

It is not just what we say but also what is written out in the community that can be confusing. Consider the cautionary sign “Watch your step”, intended to warn people about hazards on the footpath. Taken literally, a person who has their vision focussed on their feet may stumble, bump into objects or fall into a hole due to not being aware of what is up ahead.

How to help a person confused by literal interpretation of language

Carol Gray, author of many practical resources to help individuals with autism, suggests that the social difficulties in autism should be viewed as a ‘shared impairment’ where both the person with autism and the person without have to do things differently for a successful interaction. In keeping with this, assisting individuals to overcome difficulties of literal interpretation should be a process of meeting halfway.

The person with Autism Spectrum Disorder can increase their knowledge about the true meaning of some commonly used sayings. The person without can adapt their language so there is a reduction in confusing sayings.

Some great books to help with understanding of figurative speech are:

What did you say? What did you mean? Jude Welton, Jessica Kingsley, 2004. This book is an illustrated guide to metaphors. Each page shows a saying, along with a picture of how a person interpreting the saying literally may understand the saying to mean. Each page also has an explanation of what the saying really means, and when to use it. Suitable for upper primary age (8 years) onwards.

An Asperger Dictionary of Everyday

Expressions, Ian Stuart-Hamilton, Jessica Kingsley, 2004. This book contains thousands of sayings that are confusing when interpreted literally. The dictionary explains in concrete terms what each statement is really trying to convey. An excellent feature of the dictionary is a politeness rating for each statement. A person with an Autism Spectrum Disorder can then determine which statements should be used, and which should be avoided, as they may offend other people. Suitable for lower secondary age (12 years) and onwards.

References:

¹ No. 1337 - Thinking in Pictures, Temple Grandin, Vintage Books, 1995.

² www.thegraycenter.org

Preparing for a Successful Transition

reprinted from Autism New WA Aug 2006 Autism Association of Western Australia

This is an important time of the year to start planning for the transition of children to school. Whether it is the transition from one year to-the next, or the transition to a new school environment, it is a busy time and planning and preparation are essential. This article will outline some strategies for preparing for transitions. It will also provide a brief overview of some of the school-aged services available to children with autism and their families.

TRANSITION PLANNING IN GENERAL

Preparation is the key. Students with autism rely on routine and repetition to learn new skills and to feel comfortable in a new environment. It is therefore important to work with their strengths and use these strategies to facilitate a safe and successful transition.

Talk to the teacher and work together to create an information pack for the new people to be involved in your child’s education. This is often called a “passport”

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and it contains all of the most important information to assist the child. The following is an example of "passport" information:

John's Passport

Sensory Requirements (Does John need frequent breaks?)

Visuals (Does John use Compics/photos/PECS?)

Play (What are John's favorite toys/Activities?)

Friends (Who are the children with whom John likes to play?)

Calming tips (What things help John to calm down?)

Behaviour (How do we know when John is becoming distressed?)

PLAN AHEAD

If your child is moving into a completely new environment with great demands, negotiate with the teacher to have your child commence with shorter days until they build up their confidence in their new surroundings. Success will build confidence and that will help the child to feel happy and willing to come to school the next day

PREPARATION FOR A NEW SCHOOL

If you are choosing a new school for your child, or if your child is moving up a grade at the end of the year, it is important to plan ahead.

When choosing a new school for your child it is important to first write down your goals/ideas you want for your child. The first step is to find out about the schools that are available in your area. Once you have chosen a number of schools, make a time to meet with the Principal of each school. Bring a list of questions to the meeting and get a feel for how the school is likely to respond to you and your child's needs. Ask about aide-time and what they have found best in working with children with autism in the past. In some schools it may be easy to match a teaching style to a child's learning style. A classroom that uses lots of visual supports and structure is a great environment for a child with autism.

The following are some basic guidelines to get you started when preparing for transition to a new school or a new classroom.

FIRST DAY AT SCHOOL

On the first day of school, the child should be familiar

with the environment and their new teacher. However, to ease the child's stress during this transition period, negotiate with the teacher in advance for your child to have regular breaks, if necessary, especially in the first few weeks. In the break periods, incorporate tasks with which the child feels successful and that are not too demanding.

Plan the separation from mum/dad at the beginning of the day. It might be a good idea for your child to arrive earlier to avoid the rush period and to settle in. Have an activity prepared which the child can engage in so that there is immediate structure and a distraction from separating from mum/dad.

Photos and schedules prepared for the first day will greatly ease the child into the routine. Talk to your teacher about your child's representational level i.e. whether s/he is best with Compics, photos or the written word.

Over the first week and onwards.....

Allow time and space for the new teacher and/or aide to establish rapport with your child. Don't expect everything to run smoothly from the first day.

Always anticipate a settling-in period of a few weeks.

Be available to answer questions with the teacher/aide and to work through any difficulties in a positive way. Ask the teacher to make a regular time to meet with you to discuss your child's progress; and also use a communication book between home and school.

Several weeks into the new Term....

(Education Plan)

Discuss how the teacher feels about the two-way communication and if either of you have any suggestions for improvement. Also discuss the best ways to involve therapy staff.

GOING UP GRADES

If your child is moving up year groups it is important to plan ahead for the transition. A change of routine or a change of environment can be quite distressing for the child with autism. Consequently, it is important to work with your child's teacher and aide to make this transition run smoothly.

A good time to start is in the final term of the school year. Ask your school if they can establish transition activities involving your child and perhaps some of their

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peers. The group can visit the new classroom so that familiarity with the new environment can be established. For children with good verbal skills a social story can be developed in order to help them to make sense of the upcoming transition. Begin systematic visitation to the new classroom and new play areas.

It is also a good idea for some children to visit the new classroom in the holidays prior to starting in the new year. This will allow them to familiarise themselves with the environment during a time that it is quieter and free from distractions. The child can be shown where the toilets are; where to hang up their bag and where they will be required to sit when they first start.

Organise a regular time with your child's classroom teacher to talk about your child's progress and the level of modifications required for successful transition. Also make a time each day to communicate with the classroom aide about how your child is responding. Also remember, that a communication book can be a very good tool for detailed communication with the aide.

USING A SOCIAL STORY

If the child has good verbal skills, a social story can help them to understand the planned change. Include photos of the new teacher/aide and the different environments your child will encounter. Remember, the social story can also be used to convey the social rules of the new environment which the child with autism can often find

difficult. The following is an example of a story used with a child who had great difficulty in not being able to speak at whatever time he wished in class; and not being able to answer ALL the questions ie letting other children take a turn

Through use of the social story, instructions can become part of a repeated routine. It also allows the child to focus on the story (under direction) when they are having difficulty with the rules. So instead of a one-on-one battle about, for example, when you are allowed to speak out in class, the issue becomes one of "what does our social story tell us?" An example of a social story for asking questions:

When I am in class, sometimes I have a question.

When I want to ask a question, I raise my hand and wait until the teacher calls my name.

If I raise my hand, the teacher will know I would like to ask a question.

When the teacher calls my name, it is my turn to ask my question.

The teacher will answer my question.

I will try to listen carefully to my teacher's answer.

Other children may have questions, too.

Sometimes my teacher will call another child's name.

I will wait patiently and quietly until my teacher calls on me to ask my Question..

Autism Tasmania: Annual General Meeting

At the AGM in September the following office bearers were elected:

President:	Mrs Penny Cromarty
Vice Presidents	Dr Andrew Davies, Mrs Ros Ward
Secretary:	Mr Mick Clark
Treasurer:	Mr Neil Gardner
Committee:	Mr Peter Hatters, Ms Sue Brown,

Mrs Carolyn Moore was appointed to a casual position at the Nov. meeting.

This Committee works on a voluntary basis for the benefit of the Autism Community throughout the state. Most are parents of children/adults on the Autism spectrum but also bring a variety of skills to the Committee. Amongst the committee are a Company Director, University Lecturer, Teacher, Organisational Consultant, retired Public Servant, Employment Consultant and a Speech Pathologist.

Stress, Mood and Behaviours in Children and Adolescents with Autism Participants Required (Parents/Guardians of a child with Autism (ages 4-18))

Flapping arms and hands, creating order through repetitive and compulsive routines, low self-esteem, hostility and self-injurious behaviours are all thought to be important means of coping with stress and anxiety for individuals with a developmental disability such as Autism. Whilst there is an abundance of literature available that discusses issues relevant to stress and mood within the general population and in a variety of different environments, there is limited information on how it applies to individuals with Autism. Previous research has shown consistently strong evidence of a relationship between high stress levels and parents or caregivers of a child with autism (Olsson & Hwang, 2002, & Innstrand, Espnes & Myketun, 2002), however few attempts have yet been made to explore how stress and mood can hinder the well-being amongst people with autism. When tasks become confusing, frustrating, or 'different', anxiety triggers avoidance behaviours such as becoming unfocused and unresponsive, self-stimulatory actions (e.g., flapping arms, making noises, or creating order by lining up objects) or self-injurious behaviour such as biting and banging their heads against floors, walls or other solid surfaces. In her book 'Nobody Nowhere' (Williams, 1992), Donna Williams explained that behaviours such as rocking, hand-shaking, head banging, flicking objects and chin tapping provided her with the security and release from built up anxiety and tension. The behaviours and compulsive routines that appear so characteristic of individuals with autism are not so abnormal if they are viewed as manifestations of someone under severe stress, and with few alternative ways of expression (Jordan, 2000).

Dear Parent/Guardian,

I am writing to request your support and participation in a research project being undertaken by Meroë Robertson and Dr Paul Bramston from the University of Southern Queensland.

The overall research is looking at assessing how stress and mood factors may contribute to the behaviours displayed in children and adolescents with autism. A major focus of the research will be on the role of stress in coping with life factors for individuals with autism and the coping or avoidance behaviours that result from this stress. Mood factors will also be explored in order to understand if these mood states influence the behaviours that result from the environmental stressors.

It is hoped that the results from this study will contribute to a greater understanding of the behaviours that are

characteristic of autism and may be of practical benefit to those who live and work with people with autism.

The study can be conducted in your house and at your own pace. It will involve you completing 3 questionnaires that will take approximately 30 – 60 minutes. The first questionnaire asks you to rate the intensity of stress your child experiences to a range of issues. The second questionnaire asks you indicate how you think your child has felt in the last two weeks according to a number of mood states and the final questionnaire asks you to rate the behaviours of your child over the last six months.

All information will be treated in strict confidence and no names will be used in any reports written about in the study. Should you decide to withdraw from the study at a later date, you are free to do so.

Please contact Meroë Robertson for any further information and to obtain a survey package: meroe.robertson@disability.qld.gov.au

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BOOK Review

Title 'Not Even Wrong' – Paul Collins

Subtitled "A Father's Journey into the Lost History of Autism", this exceptionally written and imaginative book blends Paul Collins' personal experiences as a father of a young autistic son with a fantastic journey through the history of autism, examining early stories, forgotten geniuses and obscure medical history. By an extraordinary coincidence, at the time his son was diagnosed the author was researching Peter the Wild Boy, the feral child of King George I's court and probably one of the first recorded cases of autism. A must read if you want to understand how early theories of neurology have led us to contemporary understandings of the autism spectrum disorders

Bernard Rimland Obituary: 28 November 2006. The Independent

Psychologist researcher into Autism who overturned the theory that it was a reaction to bad parenting Bernard Rimland, psychologist: born Cleveland, Ohio 15 November 1928; Founder, Autism Society of America 1965; Founder, Autism Research Institute 1967; married 1951 Gloria Alf (two sons, one daughter); died San Diego, California 21 November 2006.

The psychologist Bernard Rimland was a tireless researcher who brought hope to thousands of autistic children and their parents, destroying the myth, once prevalent, that autism was an emotional disorder caused by "refrigerator mothers".

Despite having taken a degree in Psychology at San Diego State University, followed by a PhD in Experimental Psychology at Pennsylvania State University, Rimland had never come across the term "autism" when his first son, Mark, was born, with obvious developmental problems, in 1956. As he told me many years later,

We had no idea what was going on. Our paediatrician was totally baffled. Then my wife Gloria remembered reading in one of my college textbooks about a child wandering around, staring into space, not recognising people and so forth; we looked it up and there was the word "autism".

Although the term had been coined by Eugen Beiler in 1911, the first clinical description of autism, by Leo Kanner, only dated from 1943, and in the Fifties the condition was still rare and poorly understood. As soon as his son was diagnosed, Rimland threw himself into what became a lifelong quest to research the whole range of what are now called "autism spectrum disorders".

He soon found himself in direct conflict with the child psychologist Bruno Bettelheim, who believed that autism was a reaction to bad parenting. Bettelheim eventually expounded this damaging thesis in his 1967 book *The Empty Fortress*. Meanwhile, determined to disprove Bettelheim, Rimland scoured all the available research literature, finding not a scrap of evidence to support the theory. His own book *Infantile Autism: the syndrome and its implications for a neural theory of behavior* (1964) insisted that autism was a biological disorder which could be treated - or at least ameliorated - with biomedical and behavioural therapies.

For the rest of his life Rimland devoted every spare moment to amassing a vast database of research and case histories, founding the Autism Society of America in 1965 and the Autism Research Institute (ARI) in 1967. Perhaps his greatest contribution to the treatment of autistic children was his championing of Applied Behavioural Analysis (ABA) - an educational approach pioneered by the Norwegian psychologist Ivar Lovaas at UCLA (the University of California, Los Angeles). Based on a series of drills, starting with very simple instructions, building up to successively more complex instructions, punctiliously rewarding success at every stage, the method has helped many autistic children not only to gain the first rudiments of language, but also to begin to understand normal social behaviour.

One-to-one ABA teaching has helped many autistic children - particularly the higher functioning ones - to progress from home education or special units to mainstream education, and now has wide acceptance in the professional autism world. Rimland's views on the biological causes - and biomedical treatments - of autism remain more controversial. He always acknowledged the likelihood of a genetic component in autism spectrum disorders. However, he was also convinced that, with many children, this genetic susceptibility was triggered by external insults.

When I last spoke to him, he cited three main categories: environmental pollutants such as agricultural products, car emissions and food colourings; antibiotics destroying beneficial bacteria and giving rise to candida; and, most controversially, "medical pollution" from vaccinations. He was convinced that thimerosal - the mercury-based preservative used in the DPT triple jab (against diphtheria, pertussis and tetanus) - was a likely cause of autism. He also supported the demonised gastroenterologist Andrew Wakefield's suggestion that the interaction of live viruses in the MMR injection (against measles, mumps and rubella) could be another cause of autism, pointing out the huge increase of late-onset autism during the 1980s, when MMR was introduced.

After retiring from his post as a naval psychologist in 1985, Rimland spent all his time, seven days a week, in the Autism Research Institute office at his home in San

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Diego. Amassing over 37,000 case histories, he insisted that there had been a vast increase in the incidence of autism. The standard riposte - that doctors have become more aware of the condition and better at diagnosing it - cut no ice with him. Testifying before the House Committee on Government Reform in April 2000, he stated, "That is nonsense. Any paediatrician, teacher or school official with 20 or more years experience will confirm . . . [that] there is a real increase in autism and the numbers are rising."

His views on biomedical treatments were equally controversial. He advocated vitamin supplements - in particular large doses of vitamin B6 with magnesium - and, for some children, gluten- and casein-free diets. Many medical professionals dismissed his ideas as cranky theories lacking any supporting evidence; but thousands of parents thought differently, or at the very least found that diet and supplements seemed to make the lives of their autistic children easier.

Parents' evidence can always be dismissed as being unreliably subjective; nevertheless, Rimland's basic theory, and that of other researchers in the field - that many autistic children have weak immune systems and digestive systems which make them both vulnerable to

environmental insults and poor at absorbing nutrients - does make a lot of sense. His mission was to find ways of treating that fragility.

Rimland was expert adviser to the Hollywood movie *Rain Man* (1988). Although Dustin Hoffman's brilliant performance as the uncannily numerate autistic savant left many people with the assumption that all autists must be brilliant mathematicians, artists or musicians - only a tiny minority actually have those "savant" skills - the film did at least make the public much more aware of autism in general. For Rimland, Hollywood was just a brief diversion from the work of the ARI, from where he trawled the world's research papers, amassing a vast database on every aspect of autism research and sharing new discoveries in his quarterly newsletter. He often worked late into the night, answering letters and e-mails from parents, or discussing treatments on the telephone, always ready to share information and fanatical to the end in his quest to keep exploring the autism spectrum disorders about which so much is still unknown.

His son Mark grew up to become a successful artist, and Rimland and his wife had another son, Paul, and a daughter, Helen.

Stephen Venables

Memberships Due

Membership renewals for 2007 have been posted this week and are due from 31 December 2006. Under our current policy, all members approved after 1 October are given a carryover membership until the end of the following year, although this will change next year to only cover new rather than renewing members.

Please pay your 2007 membership by 31 March 2007 to keep continuity of membership. After this date you cease to be a member and will miss out on newsletters, seminar and conference information and access to the library.

Hobart Show Thanks

Our thanks to Autism Tasmania members Mick Clark, Neil Gardner, Mike & Barbara Stewart, Keith Heard & Carol Webster, Leesa Glidden & Janne Percival who volunteered and worked at the Hobart Show this year, along with students from The Friends School. Weather conditions covered the full range - 27°C on Tuesday afternoon while setting up, to snow and sleet on Saturday! Despite the conditions, the event was a financial success, raising over \$1600. This was \$500 more than the previous year and better than we budgeted. Roll on Agfest in May 2007.!

Wendy Lawson Visit – Devonport 26/11/06 by Mary Brake

I informed my family that we were all booked in to hear Wendy Lawson speak in Devonport on Sunday, 26th November.

'And who is Wendy Lawson?' my young daughter asked. I explained that Wendy is a world renowned speaker on the subject of autism, and that she has Aspergers herself.

I went on to justify to my children why their Sunday had been planned for them without their consent... I hoped that by their meeting of Wendy and hearing her speak they might better understand their older sibling who causes them great frustration. They might through greater understanding accept her ways more readily, become less frustrated AND afford her increased respect. – High hopes all for a Sunday afternoon!

Entering the room of the venue is big impact for me when a group of people with an ASD are gathered. The room is quiet, heads are down, there is a tension in the air and a certain discomfort. I feel big and gauche, too self-assured and too 'strong'. I feel that I have entered a gentle and in some ways fragile community and that I must tread softly, quietly and carefully.

Wendy spoke about ways of being different. I was familiar with most of her material already, and it is very accessible through her many published books. It was the unplanned teaching that I found the most interesting. Coming strongly through her address and answers to questions was Wendy's conviction that an Autism Spectrum Disorder (ASD) is actually not a disorder but a *condition*. (ASC) I highly respect Wendy's perspective, but for the sake of common terminology will continue with ASD in this article. The different perspective and 'being' of individuals with an ASD is simply an alternative idea to common expectations. Wendy described how that fear causes us to hide, to run, to criticise and/or attempt to make the fear go away. She believes that the inclusion of students with an ASD into mainstream schooling is fraught with problems and cannot possibly work effectively. We fear what we don't understand – and this means that we often fear each other. The ASD world and the typical world often become confused by each other. This of course will result in fear leading to hiding, running, criticising and/or attempting to make the person causing the fear to go away.

Autism is not a disability. It is a *diffability*. It is a different

idea to a common expectation. Wendy mused over the fact that neurotypical (individuals who typically fit 'the norm') people described those with an ASD as often having *enhanced* perceptual functioning. Surely the truth is more that neurotypical individuals have *inferior* or *impaired* perceptual functioning. Why does the ASD individual always have to be singled out as the deviation? Wendy emphasises again that our ideas and perceptions need to correspond to our own concept of 'normal' to enable us to accommodate the other – otherwise the result is fear.

Neurotypicals tend to see difference as disability. Wendy told of the time that she realised that she was different – it was the beginning of a road of despair for her. Difference needs to be **CELEBRATED!!** Difference is not a disability. It is simply a different way of being. Wendy informed us that anxiety and depression are experienced by 2-13% in a typical population. This increases radically to 30% in the ASD population. This is not surprising when messages are constantly given to people who are different that they are 'not OK' as they are. Wendy said "I don't want anyone to change who I am, but, just like you, I do want to be heard, understood and accommodated." Why can't neurotypicals accept people being different? They seem to be very rigid in their thinking about who is or isn't ok. Wendy asks 'is there a tablet for that?'

It was almost gleefully that Wendy excitedly shared some 'funny' words from the back of one of her books. She had mentioned the toilet during her discourse and suddenly stopped and asked 'Can I say that here? Is that ok?' She went on to explain that in America you must not say 'toilet' but rather 'restroom'. She very matter-of-factly went to say that you can't rest for very long though or people come looking for you. In the UK she explained you must say 'bathroom' – and there is no bath in the room at all! It's odd! she exclaimed.

That reminded Wendy of some words that she has collected and written in a chapter in one of her books. In primary school the teacher told Wendy to 'get changed'. Into what? Now that's a scary thought! Then she was often told to 'get to sleep'. She knew how to get to the corner store, but there was no map to get to sleep. No-one ever told her how to get there. At times,

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neurotypicals have been wary of 'aspies' Wendy says. They are worried that the aspies behaviour might rub off onto their child. Isn't that weird! Wendy exclaims – behaviour rubbing off! A member of the audience shared that when her car wouldn't start her mum told her that it must have a flat battery. She looked under the bonnet, but the battery was still square. Despite this, her mother insisted that it was flat.

So, what of my hopes for my family... as the session concluded my son said 'that was amazing'. I understand so much more! I didn't know that *** **can't** change, I just thought that she wouldn't! Now I won't keep trying to make her – she just *can't*, can she? All you parents know, it only makes sense if someone other than yourself says it - so don't waste your breath!

Paul, - father of a young 'aspie' says 'that was an insightful look **right inside!**'

Ebony (7 y.o aspie sibling) says 'you have to be kind, look after and understand people with Aspergers'

Peter (a father) says 'I went to learn about my daughter, but ended up learning more about myself!'

Joe (5yo) sat through a 1½ hour car journey and then

the address and was so good that Wendy complimented him.

Rachel (a mother) says 'Some things just can't be read in a book. It was inspiring and challenging and a great forum for people to get immediate answers to questions.

Bonnie (9yo aspie) says 'Wendy is nice. She explained things that I felt like'

Sam (16yo) says that he got to understand that firm beliefs are not going to change. Interestingly he found the manner in which he (along with the rest of the group) was referred to as 'neurotypical' – and 'isn't there a pill for that?' a bit insulting. Evidently he was privileged to be able to experience what it was like 'from the other side'!

Finally, a reminder from Wendy that people with an ASD have as much difficulty understanding those of us who are neurotypical, as we do them. It's all about understanding and accommodating each other. And on that thought says Wendy, Google 'Institute for the study of the neurotypical'.

Mary Brake

Autism Council of Australia Changes

At a Special General Meeting of the Autism Council of Australia on Friday, 24 November 2006, members decided to adopt a new constitution for the organisation and a new name. The new constitution simplifies its organisational requirements and allows the organisation to be very focused on its job, which is to collect and disseminate information, raise awareness, promote research and contribute to policy development in all areas which affect the community of people affected by autism spectrum disorders in Australia and in particular, bring this to the attention of the federal government and the broader community. A full copy of the constitution can be found on its web site at <http://www.autismaus.com.au/aca/constitution.html>.

The new name of the Council is the *Australian Advisory Board on Autism Spectrum Disorders*. It is most significant that the national group has adopted a name which focuses on the whole spectrum of autism disorders, not just autism. Secondly, the name reflects the fact that

the national body is made up of eight directors who represent each of the major autism organisations based in each state and territory around Australia. Together the directors form a board which can advise both the federal government and the community at large on issues relating to autism spectrum disorders.

These changes have been carefully and deliberately considered over the past year. The previous constitution, although designed collaboratively and with good intent was not workable with the limited resources available to the national group. To date, attempts to secure federal government funding have been unsuccessful; consequently the national group continues to rely on fees and time from each of its eight corporate members to undertake its work. This new constitution provides a simple, clear and effective solution for how it can move forward.

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There have also been changes of office bearers for the coming year. The Chairperson is Adrian Ford from Aspect (formerly the Autism Assoc of NSW), with Mick Clark from Autism Tasmania as the Deputy Chairperson, Jon Martin from Autism SA as Honorary Treasurer and Amanda Golding from Autism Victoria as Secretary. The other Directors on the Board are Penny Beeston (Autism Queensland), Alison Bird (Autism NT), Bob Buckley (Autism Asperger ACT) and Val McKelvey (Autism Association of WA). Aspect will continue to provide the resources of a small secretariat to the Advisory Board, under a continuing service contract.

Early in 2007 the Advisory Board will be releasing a major report on the prevalence of autism spectrum disorders in Australia which is based on epidemiological research which has been conducted and gives for the first time the prevalence rate across Australia. The

Advisory Board will also be coordinating a national Autism Awareness Week (13 – 19 May 2007) focusing on the theme *Creative Futures* - the same theme as the Australian Biennial Conference on Autism Spectrum Disorders to be held on the Gold Coast on 14 – 16 March 2007.

These are important steps forward and are the result of considerable work over the last 18 months. The Advisory Board appreciates the support it has received from its various corporate members as it has been preparing for this change and directors look forward to working together with the corporate members to achieve a more effective national voice for the community of people affected by Autism Spectrum Disorders.

Mick Clark

BOOK Reviews

Title: ASPoetry Author: Wendy Lawson

Reviewer: Allana Robson

Wendy Lawson's ASPoetry offers up a potent mix of equal part observation and revelation that combine to deliver a feast of inspiration. Writing from the perspective of a fully mature female poet with a profoundly keen eye for the paradoxes that nestles within the currency of our common language, Lawson exposes the world of contrast at play inside all of us. At the same time, her work is a joyous celebration of the many differences that lay between the said and the unsaid, the seen and the unseen, the real and the surreal that operate within the space of a second, a day, a week or a lifetime.

Lawson delivers a beautifully raw and honest perspective of the human condition as only she can. She asks the questions we all secretly crave the answers for and in so doing provides a platform from which to consider, evaluate and better understand our own motivating forces. This is a book as much about the pure essence of life as it is about the dichotomy of words and the conundrum of being. Well worth a first, second, third and even a fourth read.

Title: Coming Out Asperger; Diagnosis, Disclosure and Self-Confidence

Reviewer: Carolyn Moore

I enjoy reading the personal accounts of people with AS. The ones in this book are a mixture of both positive and negative life experiences and, it seemed to me that the attitudes and reactions of those closest to, or with the most influence on the diagnosed person had huge bearing on that person's present day attitude to themselves, their self-confidence and self-esteem.

It brought home the huge responsibility I have as the parent of a child with AS, to be very aware of the terms I use when discussing AS.

I particularly liked the concept of "soft" disclosure. This takes away the pressure of "where on earth to begin" and allows far greater freedom of choice, which I think is empowering and is something I can take away and use.

I had to get the dictionary out a few times and you need to have an understanding of the terms used, but it was an interesting read and I recommend anyone with AS or an interest in AS to read it.

Grant Helps Shape New Direction

A grant from the Tasmanian Community Fund over the last 2 years has enabled Autism Tasmania to boost support groups around the State and introduce specific programs that will give far more effective and sustainable support to parents and families, help people work together for their common benefit and better use the limited resources of the Association's part-time Family Support Co-ordinator [FSC].

President, Penny Cromarty said that the project has shone new light on the role and the services the Association can provide to its members and the autism community.

"The result is a more comprehensive, integrated service model that can be progressively developed as resources become available and the organisation grows", she said.

Twelve parent/family support groups now meet regularly throughout the State. In addition to working with parents to consolidate current groups, Family Support Co-ordinator, Rose Clark has successfully established additional groups in regional areas such as Circular Head and the Huon Valley. A significant milestone was the creation of a specific group for adults with Asperger's Syndrome in Hobart.

Discussions are well advanced to adopt the proven 'Someone to turn to ...'TM program under an arrangement with Aspect [Autism Spectrum Australia, formerly the Autism Assoc of NSW] and Autism SA [South Australia]. A small group of parent volunteers will be trained in communication, telephone communication, grief and loss and caring for carers. This program will operate separately from but in a complimentary way with support groups.

Also under development is a leadership program for people

involved in co-ordinating or facilitating parent support groups, based on the *Carer Support Group Facilitator Training* model run by Carers Tasmania through the Commonwealth Carer Respite Centre.

It is expected that both these programs will start in March/April 2007, after the summer holiday season and children have returned to school. As these programs are introduced, the FSC role will have more emphasis on supporting the parent volunteers, group leaders, bringing together speakers and training for the different groups and less direct group involvement and travel.

Penny Cromarty explained that these elements build on initiatives already taken to simplify information, support and training contact through a single telephone number, improvements to the website as a point of contact, the re-introduction of the members' library and the opening of an administrative office in the Giant Steps Centre at Deloraine.

"Until on-going government support is secured, Autism Tasmania has to find the right balance between paid and volunteer resources," she said.

"We've also been able to identify opportunities to improve the seminar and conference programs that we offer to parents and professionals alike and extend our growing services in training to service providers in the sector," she added.

Look out for further announcements about these programs and other initiatives in the first few months of 2007.

Companion Card

In the last issue of autism news we advised about the impending availability of the companion card. The Companion Card is a major initiative of the Government's Disability Framework for Action. It is a wallet sized photo ID card for people who, due to their disability, require lifelong attendant care support to participate at community venues and activities.

Who is eligible?

To be eligible for a Tasmanian Companion Card, you must be able to demonstrate all of the following: You live in Tasmania; and you have a disability; and due to the impact of your disability, you are unable to participate at most community venues or activities without attendant care type support; and your need for this level of support will be lifelong.

Who is a companion?

A companion may be a paid or unpaid person whose primary purpose for attending a venue or event is to provide attendant care support to enable the cardholder to participate in an activity or event. Cardholders can choose their companion, and this may vary depending on the activity and the occasion.

The Cardholder Handbook has all the information you will require to determine if you are eligible.

How to Apply

Visit the website at www.companioncard.org.au and go to the Tasmania link. Alternatively telephone the Disability Bureau Enquiry Line on 1800 009 501 to request the Cardholder Handbook and the Cardholder Application Form to be sent to you.



THE NEWSLETTER OF
AUTISM TASMANIA
INC.

Postal Address: PO Box 1552

Launceston, Tasmania 7250

www.autismtas.org.au

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

Family Support

Contact the
Autism Tasmania
Family Support
Coordinator,
Rose Clark
on

6423 2288 or

0407 320 048

or

autism@autismtas.org.au

This newsletter is produced
with the kind support
of the office of
Michael Ferguson - MHR Bass

LEAVE ARRANGEMENTS – Rose on Leave

Please note that Family Support Coordinator, Rose Clark will be on holidays as from December 29th until the end of January. We recognise that while it is necessary for Rose to have a break, the holiday period can be a difficult time for some families. If you require urgent assistance only, you may leave a message on Rose's mobile (0407 320 048) and she will endeavour to get back to you.

Alternatively, contact Lifeline for immediate assistance.

Autism Tasmania Support Groups

South

South – meet on the second Thursday evening in each month at Tascare, 231 Main Road, Moonah starting at 7.30pm. There is a coffee morning the following day, the second Friday (sometimes this is the 3rd according to how the days fall at the beginning of the month) at Munchkins, in Sandy Bay, meeting from 9.30 onwards. (Munchkins is located above Woolworths supermarket and is very suitable for young children.)

Cygnnet /Huonville - meetings as requested by parents – either in Cygnnet or Huonville.

North

North – Notices will be sent out.

Exeter – meet on the last Friday in each month at Tresca in Exeter, beginning at 10am.

George Town – meet on the last Wednesday evening of each month beginning at 7.30pm at the Wattle Group building (located at the roundabout in Agnes Street, George Town).

NW and East Coasts

North West – The parent group meets on the first Tuesday evening in each month at the Community Health Centre, Jones Street, Burnie (other venues according to speakers etc.)

Sheffield – details of meetings will be sent out

Smithton – meet on the second Wednesday of every month at the Rural Health Centre in Smithton.

East Coast – meet at Scamander on days decided by parents. For meeting times and details phone Karen Rawnsley on 6372 5077