



PRESIDENT'S MESSAGE

Welcome to this edition of Autism News. Inside you will find two major articles which although at times similar, may help newer members in particular to better understand the complexities of Autism Spectrum Disorder.

National Autism Awareness Week is in May, and I urge you to participate in one of the two Afternoons about Autism which will occur on Sat 19th and Sunday 20th May in Launceston and Hobart. Geraldine Robertson and Kate Wilson will each present a session followed by questions. Further information is included in this edition.

The Saturday afternoon session will include the presentation of the inaugural Alex Walley Memorial Awards. These awards have been established in memory of Alex, a young boy with ASD who died suddenly several years ago. The awards were instigated by his parents, Mike and Sue Walley, in conjunction with Autism Tasmania. The Awards will recognise positive contributions made by individuals or organisations within the Tasmanian autism community. The recipients will be announced in the next edition of Autism News.

Unfortunately the proposed Statewide Conference, previously held in 2003 and 2005 has been postponed. Autism Tasmania has put in a grant application for funds to assist with the running of such a conference and we hope to have more news about this for you soon.

The Family Support coordinator, Rose Clark attended the National Biennial Autism Conference on the Gold Coast recently and I hope that you will ask her about it at the various support group meetings that she attends in the next few weeks.

As the year progresses, we expect that Rose's role will change. Autism Tasmania recently completed an

investigation into the way in which it could best support people with autism, their families and carers. This was funded by a grant from the Tasmanian Community Fund. While the support groups are seen as an integral part of the support service that Autism Tasmania offers, it is not financially possible for Rose to continue to travel around the state to the meetings as often as she has in the past. In the next few weeks we will be looking to establish a program called *Someone to Turn To* where volunteers are trained to become phone counsellors as part of a statewide network which will provide support and advice for people with autism, their families and carers. This program operates in South Australia. To ensure the viability and continuity of the support groups Autism Tasmania is also seeking support group members who would be willing to step up to the role of group leader, and will provide some training for this.

This will allow Rose to concentrate more on training government and community groups, organise seminars as well as to support the *Someone to Turn To* volunteers and the new support group leaders.

To those of you who live in the north, come and see us at our two sites at Agfest in early May. This is a major fundraising venture supported by National Foods. Phone Mick Clark (0417 354 157) if you would like to assist with selling milk at that time. Thank you to those who have already volunteered.

Penny Cromarty

National Autism Awareness Week May 13th—20th 2007

THE ALEX WALLEY MEMORIAL AWARDS

The inaugural Alex Walley Memorial Awards will be presented on Saturday 19th May in Launceston during National Autism Awareness Week and will be presented annually thereafter. These awards have been instigated by Alex's parents, Mike and Sue Walley in conjunction with Autism Tasmania, in memory of Alex and to recognise the many contributions and achievements made to the field of ASD and by individuals with an ASD. Nominations are invited in two categories and we encourage you to nominate an individual or organisation that you believe is worthy of these awards. Awards will be presented to:

- i) individuals or organisations who have made an outstanding contribution to the field of Autism Spectrum Disorder in Tasmania and
- ii) to individuals of any age with an Autism Spectrum Disorder to recognise personal achievement.

Detailed information about the awards including background information about Alex and an official nomination form, has been sent to all members. We urge you to participate in this most worthy event where we can recognise personal achievement by individuals with an ASD no matter how big and small and acknowledge the achievements of those who have made a positive contribution to improving the lives of those with an ASD and their families in Tasmania.

AN AFTERNOON ON AUTISM SPECTRUM DISORDER

**Saturday 19th May 2007,
Archers Manor, Launceston**

1.30 – 4pm

featuring

Ms Geraldine Robertson

The Alex Walley Awards will be presented in Launceston on this day.

**Sunday 20th May 2007,
The Mercure Hotel, Hobart**

1.30 – 4.00pm

featuring

Ms Kate Wilson

Geraldine Robertson has Asperger's Syndrome and is a teacher with the Department of Education. She has presented at several conferences, offering a personal insight into Asperger Syndrome.

Kate Wilson is the Early Years Autism Consultant in Hobart with the Department of Education and has recently returned from the United States on a Hardie Fellowship.

Geraldine and Kate both have extensive knowledge and understanding of Autism Spectrum Disorders and will focus on how to create an autism friendly environment.

Cost: \$25.00 per person

\$15.00 concession (Persons with an ASD, Students, Health Care Card Holders,)

Please complete the registration form and forward to Autism Tasmania.

Contact Rose Clark for further information on 6423 2288 or email Rose at mrtclark@bigpond.net.au

The 2007 Biennial Australian Conference on Autism Spectrum Disorder Report

The national conference was held between 14th – 16th March at the Royal Pines Resort on the Gold Coast. The title of the conference was Creative Futures.

Key note speakers who addressed the approximately 530 delegates were: Dr Rita Jordan, Professor in Autism Studies at the centre for Education and Research at the University of Birmingham; Dr Brenda Smith Myles, Chief of Programs and Development, Ohio Centre for Autism and Low Incidence, Associate Professor at the University of Kansas and Dr Catherine Lord, Professor of Psychology, Psychiatry and Paediatrics at the University of Michigan.

The keynote speakers were excellent presenting very informative, innovative and in some cases first time papers. Dr Rita Jordan and Dr Brenda Smith Myles presented papers that were very practically based and full of excellent ideas and strategies. Rita Jordan's first presentation was Social Inclusion and Autism Spectrum Disorder which really addressed the issues of inclusion and the tension that exists between meeting special and unique needs and enabling full inclusion in mainstream schools. Dr Brenda Smith Myles first paper was Teaching the Hidden Curriculum to Children and Youth with Autism Spectrum Disorders where she addressed the complicated world with its complicated rules, guidelines and policies – most of which are mandates and are not always consistent. The issues of toilets in the male domain was an example used where the social curriculum is accepted but not known and really talked about in general terms. Both Rita and Brenda presented a number of other extremely interesting and thought provoking papers. Dr Catherine Lord, the third international keynote concentrated on her research and the findings of that research and how it could be applied. Although interesting her presentation was very research based and required a lot of concentration when reading the data collected. Dr Catherine Lord did however address a number of important issues and I am looking forward to reading the papers.

Dr Tony Attwood was an obvious 'home grown' presenter and he didn't disappoint those listening to his

presentations. He presented two new papers that I attended, 'The Future for Children and Adults with Asperger Syndrome' and 'Surviving School Well with Asperger Syndrome: A Focus on Bullying'. Both were well researched and presented with much empathy for those on the spectrum. They will make excellent reading for our members when we obtain the papers.

Dr John Wray and his co-researchers did a wonderful job in presenting the information regarding the Prevalence Study. Although research based the paper was well balanced and VERY interesting. Information on this study has already been sent to members of Autism Tasmania.

The break out papers varied enormously in their content and quality. The time allowance of 30 minutes was really demanding both for the speakers and those who were attending – the time included moving from room-to-room which at times was difficult. I did see a paper called 'Someone to Turn To: A Parent to Parent Support Program: Overcoming the Isolation of Autism' paper. This was one of the thirty minute sessions and I certainly could have listened for a lot longer. It was a very brief overview of the program and how it works but I didn't get a very good understanding of the complexity of how those who are involved are trained and 'maintained.' Another outstanding session presented by Ms Pat Woodcock was titled, Building Bridges Over Chasms: Using Attwood's 'Exploring Feelings' workbook in Treatment of Suicide Ideation. The young person who was central to the paper was a primary school aged student with Asperger Syndrome.

Attendance at the conference enabled me to see some good displays of IT equipment and books. I brought home four books for the Autism Tasmania library: 'Ian's Walk', 'When My Worries Get Too Big!', 'Sometimes My Brother', and 'Ten Things Your Student with Autism Wishes You Knew' by Ellen Notbohm. Reviews of these four books are in this newsletter.

There were other displays at the conference that included poster displays by a range of professionals from

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around Australia that were interesting but not displayed to the best advantage for those presenting their information. As mentioned there were also book and IT displays that were great to wander around at break times. State autism organizations had booths which displayed their services, any brochures they produced as well as other merchandise: t-shirts, pens, water bottles, hats, wrist bands etc. These booths are a great way to meet people and for those who may be planning a move to another state to learn about the services that are available.

I was very fortunate to be able to attend this biennial conference as it highlighted some areas that we have been aware of in Tasmania: parent stress, the growing number of those on the spectrum, bullying issues in relation to those with an ASD and the hidden curriculum that carries with it major issues for those who venture out into the confusing world of the neuro-typical. It was disappointing that the cost of registration, travel and accommodation prevented many from attending, especially parents. There were only 7 Tasmanian delegates and many of them were there because their workplace(s) had provided funding.

The most obvious omission was that not one person who had an ASD had the opportunity to present to the whole conference. Harold Stone (from Queensland) did co-present in one of the thirty minute presentations but given the title of the conference 'Creative Futures' and the fact that we now know so many eloquent speakers within Australia who do have an Autism Spectrum Disorder this oversight was very difficult to understand.

The papers from the conference were not made available at the conference itself and will be available shortly on CD for \$50. Some of the papers will make excellent additions to future Autism Tasmania newsletters.

I would like to thank Autism Tasmania for giving me the opportunity to attend, it certainly is a wonderful way to extend your knowledge base and meet others involved in the area of Autism Spectrum Disorder.

Rose Clark

Family Support Co-ordinator

Community Achievement Award for Robert Davies

Robert Davies (year 8) received a Temple Grandin Award for "outstanding contributions to family, community and self". The award recognizes major accomplishments by those on the autism spectrum and is administered by Future Horizons Inc., an educational publishing house in the United States.

Congratulations Robert!

For further information on Future Horizons and the awards visit their website:

<http://www.fhautism.com/awards.htm>

Getting Started

The Department of Education in Tasmania has produced a booklet and accompanying DVD titled 'Getting Started'. The 'Getting Started' package is a guide for teachers of students with disabilities in regular schools and copies have been distributed to all Department of Education schools in the state. It is very well produced and all the schools and speakers on the DVD are Tasmanian. Included in the DVD are sections on: Including everyone, connecting with

families, listening to students, getting started: a teacher's perspective, building an inclusive school as well as transition, communicating, using visual schedules and working collaboratively with the many teams involved in schools. This is a wonderful resource for schools and offers a wide variety of information as well as practical strategies that can be seen in the book and in practice on the DVD.

What is Autism?

A summary of the current thinking and issues associated with Autism

Spectrum Disorder for Teachers By Dr Sian Hughes Eastern Health CAMHS

" This paper was presented by Dr Sian Hughes at a seminar for all Health Professionals on Autism Spectrum Disorders at the Royal Hobart Hospital in November 2006, convened by Dr Charlotte Whitelaw."

We now see autism as a spectrum disorder – it varies from the classic autistic child whom we would all recognise as very disabled to the more subtle cases whom we would not call autistic but who are close to the boundary between normal and autism. In between there is range of presentations, which depend on the severity of the autism symptoms and the individual's intelligence.

The person with an autism spectrum disorder may be classically autistic, high functioning autistic or have Aspergers syndrome. When they do not have all the features of an autism spectrum disorder but have some symptoms they are said to have a Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS). The table of autism types gives more information on these categories of autism.

Most of us are familiar with the classic autistic child. There are individual accounts in history, of children, who were probably autistic – the "Wild boy of Aveyron" was written in 1801 and describes a classically autistic child. The first person to connect them together was Leo Kanner in 1943– a psychiatrist from Vienna who had emigrated to the USA – he called the condition early infantile autism

He described children with no awareness of other people, inability to play normally with toys, no language or a kind of language which was not for communication, poor non verbal skills (no use of eye contact or pointing), an obsession with keeping everything the same, odd movements such as arm flapping odd responses to sensory stimuli (staring at fans, smelling everything).

At the same time fellow country man Hans Asperger still in Vienna was working with a group of children who also had poor social communication but were odd rather than aloof. They lacked imagination in their play, they could talk well but lacked an ability to converse

preferring a monologue, they had poor facial expression and odd eye contact, they were less insistent on routines but had very narrow interests, they were often ungainly and also showed odd sensory responses. Intelligence was usually good and in some cases exceptional.

They were describing children at opposites end of the same spectrum but for the next 40 years everyone focused on Kanner's description of autism.

In 1981 Uta Frith translated Asperger's work into English and with Lorna Wing (an English psychologist with a daughter who is classically autistic) the term Asperger's syndrome came into being. It took about 10 years for it to catch on – this idea of high functioning people with autism but it has now caught on and by the late 90s the diagnoses of high functioning autism were soaring.

People were looking for explanations – vaccination, mercury, gluten and casein in the diet. There have been plenty of theories but there is no scientific evidence for any of these and really this increase is simply because we are recognising the condition in children who were previously seen as a bit odd, nerdy or maybe just shy. Schools are being informed and parents are seeing newspaper articles and TV programs about autism and seeking the diagnosis.

In the 1970 1 in 2500 people were thought to be autistic - that is classical autism. Recent studies in Sydney are putting it at 1 in 200 and then if we look at all the variants of autism (Asperger's; PDD NOS) it could be as high as 1 in a 100.

Autism merges with normality at one end – Lorna Wing says if you take a man and boil away some of the water you can get Aspergers! It is more common in boys than girls (4 boys to every 1 girl) and females do tend to be more verbal and have better social skills than males.

Autism is a developmental disorder that begins before birth – it has a strong genetic component and no biological marker so like ADHD it must be diagnosed on the basis of observed and described behaviours – there

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are no tests you can do – and people have different standards so one may say yes ASD and other disagree - the same with ADHD - which makes it very difficult!!

All assessments should include the parent’s history, interaction with the child, the child’s level of intelligence, their language abilities and a report from their classroom teacher.

THE BASIC CRITERIA FOR THE AUTISM SPECTRUM ARE:

Language problems	They are often better at speaking words than understanding words
Social behaviour	They see everything from their point of view and do not understand other people
Obsessions and Routines	They get over involved in order, routines, rituals and special interests
Sensory sensitivity	They may have unusual responses to light, sounds, touch, taste, smell, pain.
Motor clumsiness	They may be uncoordinated, walk on their toes or flap their hands

These deficits lead to other difficulties

Theory of mind	Inability to realise that other people think and feel differently from you
Imagination	Inability to imagine what will happen next and predict outcomes
Anxiety	The above lead to anxiety in an aware child especially if they have an anxious personality type

LANGUAGE

The classic autistic child has very little language. They may show marked echolalia (repeat things that you have just said), speak in phrases they have heard eg from TV ads or a favourite videos. Even if they have some language they do not use it to communicate. They have better expressive language skills than receptive language skills so they can talk but have no idea what you have said to them.

Children with Aspergers may have good talking skills with

lots of vocabulary and grammar and you may think their language is good BUT they have huge problems with the pragmatics of language (see below).

Children with high functioning autism or PDD - NOS do not have good language skills for talking and have greater problems with understanding and communication but are better than the children with classical autism because their intelligence is better. They do not use the language they do have for effective communication.

Pragmatics- this is the functional use of language in social situations - to have a normal conversation you have to be aware of the other person’s state of mind and children with autism miss this completely. Once the conversation has begun there is no off switch. The child is oblivious to the listener showing distinct signs of embarrassment or desire to end the interaction. The child is not listening to or does not know how to incorporate the comments of others into the dialogue.

If asked a question they don’t understand they get confused but instead of saying ‘I don’t know’ or ‘I’m confused’ they have a tendency to pause for a long time and may then change topics to one they are familiar with.

The dialogue often turns back to the person’s favourite interests because they don’t want to look stupid and they have plenty of vocabulary and knowledge to use on their favourite topic.

They have an infuriating habit of interrupting. The skill of interrupting without causing offence or disruption is quite complex.

Semantics - Literal interpretation – They do not understand implied meanings of words and get very upset by metaphors. Tell them to “hop onto the bed” and they start hopping on one foot trying to get onto the bed. They need very clear and concise directions or they will get confused. Sarcasm and humour based on language is very confusing for them. They cannot generalise statements from one situation to another. So “don’t hit Tom” means that it is still OK to hit James.

Prosody - in conversation we change tone and volume to emphasis or indicate emotion - Asperger children may have a monotonous tone or an odd accent. The meaning of a sentence can depend on the inflection or emphasis given to one word.

Talking aloud Young children give a running commentary on their activities most have stopped this by the time they reach school but the child with autism spectrum disorder may keep going.

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Chat rooms and email conversations are great for these children. They usually like computers and on email they have time to think of an answer or seek help before they reply. There is need for eye contact or other non-verbal communication.

SOCIAL BEHAVIOUR

With the language problems and the failure to appreciate the feelings and thoughts of others social problems are inevitable.

At the extreme end they just have solitary play and no interest in anyone else and if they do let you play then there is no joint attention and they use you as a tool. At the other end some children with autism can want to be sociable and do initiate interaction but go about it the wrong way.

There is a sequence in the development of friendship as children mature they change their opinion as to what constitutes a friend. Children with autism are immature in their approach to friendship - they may say they have friends but on investigation it is no more than a casual acquaintance or wishful thinking.

They may try to copy a popular person and feel confused when they try the same activities and tell the same jokes but are just ridiculed. They misjudge the mood in a group situation. If they like someone then they assume that the other person has the same level of commitment. But they also make very loyal friends!!

The social codes of conduct are very difficult especially in adolescence because there is totally no logic to them. So children who have coped in a nice small primary can hit the wall when they get to high school.

They don't notice or misinterpret all those non-verbal cues that we send out in our body language. When they try and socialise they are often rebuffed. They ruminate on what has happened and because they are more aware they often become depressed and anxious.

INTERESTS AND ROUTINES

The fascination of a special interest and the imposition of routines that must be completed can have biggest impact on the sanity of the family. Often routines and rituals are more severe in the higher functioning children.

There is a developmental sequence in the nature of the interests and after collecting objects they move onto a topic such as trains, dinosaurs, computers or statistics.

There are several explanations for children having special interests - a special topic can facilitate conversation and indicate intelligence. It also provides order and symmetry and a means of relaxation as well as something enjoyable. By

controlling access and using the obsession constructively the child can continue to enjoy their interest and not drive others mad.

Routines are similar they make a confusing world predictable and safe.

BUT increasingly I am seeing kids with the language and the social problems but not the routines and obsessions they are often very disorganised and messy - more like ADHD but still more odd than typical ADHD and these are the ones that fit into the PDD NOS category - not typical autism but still confused by language and social interactions.

COGNITION

This is very important in diagnosis. If a child has an low IQ <75 then they will probably have poor language and social skills and to be diagnosed as autistic they must have more than this and be odd. If a child has an IQ of 120 and poor social and language skills then you need to look a bit closer for an autism diagnosis.

Profile of abilities on Intelligence tests - there is a distinct profile of abilities on intelligence testing - autistic children are good on tests which require a good vocabulary, factual knowledge, arithmetic and block design, they can give the impression of being very intelligent but they are weak on comprehension and problem solving tasks- so their overall IQ can be good but the profile is remarkably uneven. -

MOTOR CLUMSINESS

Originally this was an important part of diagnosis - Kanner saw the severe autistic children as having good motor skills and Asperger saw the higher functioning kids as having poor motor skills. In reality it is very variable and not reliable. Anecdotally I would say most children with autism spectrum problems have poor coordination but some are great. Most have difficulty with handwriting but some are wonderful artists.

Odd movements such as hand flapping, toe walking, running around in circles are more typical in low functioning children but some children with quite high IQs will flap their hands when they are distressed or walk on their toes around the edges of the playground or rock themselves as they work.

SENSORY SENSITIVITY

At least 40% of autistic children have a major problem with integration of sensory information more so those with low IQ but the higher functioning children may do as well.

They may have sensitivity in one or more of the following areas:

Light - upset by bright lights; look at fans and tops spinning

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Sound – hate loud noises, notice odd noises such as a clock ticking

Touch - stroke surfaces and very fussy about clothes next to their skin

Taste – fussy eaters may only eat one type of food

Smell - smell objects and sensitive to strange smells

Hair and teeth – hate brushing hair and teeth and visiting the hairdresser and dentist

Pain – cope with severe pain then get hysterical about a mozzie bite.

THEORY OF MIND

The theory of mind tries to explain why autistic children have these problems. A core symptom of autism is the failure of the child to show creative play. Mentally retarded non-autistic children with language and social problems show creative play at their developmental level but young autistic children do not. This led

to the realisation of an important difference between the thinking of autistic children and Alan Leslie in 1987 first proposed the theory of mind

From the age of four children understand that other people have thoughts and feelings this allows them to pretend something that is not really the case eg if Mum is using a banana as a telephone they know that she knows it is not really a telephone and so they can also believe something that to them is not true e.g. "Mum really does like my red dress and I think it is hideous". So they can manipulate representations of mental states such as pretence and belief.

Autistic children fail to appreciate other people's thoughts and feelings so they have problems with pretence and believing things that are not true. If this part of the brain is faulty then social imagination and communication skills cannot develop normally.

There are stories that provide information about a child's capacity for Theory of Mind e.g. Sally has a basket, Anne has a box, Sally puts a marble into her basket, Sally goes out for a walk, when she is out Anne, naughty Anne! takes the marble from the basket and puts it into her own box. Sally comes back in and wants to play with her marble. Where will Sally think her marble is? Where will she look? - The correct answer is in the basket where she put the marble and where she must believe her marble still is. Autistic kids expect Sally to know that the marble has been transferred even though she was not there at the time. They could not conceive Sally looking anywhere expect where the marble was because they do not understand belief. As they get

older they learn to give the correct answer but have to think much harder than their peers.

A whole series of stories like this have been developed to see if a child is able to understand other peoples thoughts at different developmental levels

IMAGINATION

It is very hard to function day by day when you cannot imagine what other people are thinking or why they are doing things. Children with high functioning autism have to think much harder than normal children and this can be exhausting for them. They may figure out what someone had said or done days after the event. For more aware people with autism, they realise that they are not good at this type of thinking and find social engagement very stressful. Often they hold it together in a structured classroom and then become more difficult at playtimes or at home when there is less structure

Most of us are good at anticipating what *might* happen in the next half an hour, the next day, even the next month or year. When things do not go the way we anticipated we are surprised but we usually have the skills to reason our way through it. Children with autism find it hard to imagine the future; this makes life very uncertain and stressful.

ANXIETY

People with autism have varying levels of anxiety just as is found in the normal population. There is a continuum of anxiety and this contributes to the variation we see in the autism spectrum. For example, it is likely that the 'passive' children with autism who have few or no rituals and routines have low anxiety levels, whereas, anxious children with autism usually have a greater number of rituals and routines in place.

We also should remind ourselves that the 'autistic' need for order and predictability is also observed in the normal population. Many people try to control their anxiety by becoming a 'bit autistic' eg, they tidy up furiously, insist on plans and routines, avoid social groups, answer in monosyllables. This creates control over one area of their life when they may be out of control in another area. Anxiety causes insecurity and by sticking to routine or acting repetitively the person feels more secure.

BRIBERY NOT PUNISHMENT

Children with autism often don't respond to punishment. The "naughty" behaviour reflects the child's difficulty in understanding the rules and mores of the social world. To be manipulative you need imagine what another person is thinking, and try to change that to your advantage – so they

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are not manipulative. They do not tell lies when they are younger but as they are older and have learnt to lie they do not do it well! Often the only way to get a child to learn new, subtle social rules is to reward them. "Bribery and Corruption" as Tony Attwood calls it. In a sense you are rewarding them for trying something difficult for them, that is, to behave in a way that does not come naturally for them.

THE AUTISM SPECTRUM

There are different levels of severity in these behaviours so there is huge individual variation. Some do not meet criteria for a diagnosis of autism and have incomplete manifestations – again those people with marked social and communication deficits but without repetitive behaviours – these deficits can cause life long impairments even though they do not meet the criteria for autism and are helped by the same services and follow the same course as those with autism.

The term PDD NOS was adopted to provide a formal diagnosis for those who shared deficits similar to autism but did not meet the full criteria. The intention was to emphasize the pervasiveness of impairments in many aspects of life while

still differentiating autism from general cognitive disabilities like mental retardation. I prefer to say that they are on the autism spectrum or have atypical autism than PDD NOS as it is such a mouthful and so meaningless for most people. The question is when does it merge with a normal personality difference and when should it be a diagnosis?

As well as having variation in the severity of the autistic symptoms much of how a child presents depends on other issues especially their IQ level, anxiety level, family and school support, other conditions such as ADHD with autism etc etc.

The straightforward high functioning child with Aspergers or HFA can be a delight to teach but you have to modify your thinking because they cannot – the ones that are difficult – who totally refuse to cooperate despite setting up wonderful programs are those who have additional problems eg oppositional defiant disorder, severe anxiety because of past events etc. Older children who have been diagnosed late and have not been properly supported can have enormous difficulties trusting the system. This can make their behaviour even more oppositional. Early intervention is vital.

Websites – Informative: Autism Spectrum Disorder

- Autism Tasmania: www.autismtas.org.au - this website is currently undergoing reconstruction but still has good, useful information
- Autism Victoria: www.autismvictoria.org.au - Autism Victoria's website is informative and has some good links
- Wendy Lawson: www.mugsy.org/wendy - this is the site of Wendy Lawson an adult who lives in Australia. Wendy has Asperger Syndrome and has recently had her eighth book published
- Tony Attwood: www.tonyattwood.com - Dr Tony Attwood is highly regarded internationally in the field of Autism Spectrum Disorder. His speciality is Asperger Syndrome
- A wonderful site for information and download printable information: www.autismhelp.info
- Autism New Zealand: www.autismnz.org.nz - another good website with general ASD information as well as New Zealand specific info
- National Autistic Society UK: www.nas.org.uk - really worth looking at
- Autism Council of Australia: www.autismaus.com.au - the website of the national autism body
- Dr Temple Grandin's website: www.templegrandin.org - Temple is an associate professor of animal sciences at Colorado University. Temple Grandin has a diagnosis of High Functioning Autism (HFA)

All of these websites also have great links to other sites.

ASD & Challenging Behaviour; Providing a choice

by Rose Clark, Family Support Co-ordinator, Autism Tasmania

Introduction

Often the words 'Autism Spectrum Disorder' and 'Challenging Behaviour' are mentioned in the same sentence. To relate to and work with people with ASD, understanding the impact the disorder has on every facet of daily life is of PARAMOUNT importance. It is essential that we understand the purpose of the 'behaviour'. It may not, in fact be challenging at all. To do this it is important to understand what Autism Spectrum Disorder is.

Autism Spectrum Disorder – What is it?

To begin with we need to understand what Autism Spectrum Disorder is! The criteria for assessment and diagnosis are set out in the DSM IVR and this is one of the steps in a diagnosis, usually after a hearing test and an examination by a paediatrician. Most parents who have gone through the process of assessment and diagnosis with their child are familiar with the assessment criteria. The child suspected of having an Autism Spectrum Disorder must display skills that lag behind his/her general level of development in the following areas:

Reciprocal Social Interaction

- Verbal and non-verbal communication
- Markedly restricted repertoire of activities/ interests, limited creative play and resistance to change

Within each of these areas are a list of behaviours that are indicative of Autism Spectrum Disorder.

In order for a diagnosis of Autism Spectrum Disorder (ASD) to be made evidence of substantial difficulty in the above areas must have been evident before the age of 36 months.

It is important to recognise that in the last 10 or so years there have been three significant alterations to the description put forward by earlier investigators and they are:

- Autism Spectrum Disorder is a life-long disorder
- The difficulties experienced by children with autism

result from delayed and atypical development in specific skill areas

- 'Unusual' parent-child interactions do not cause autism

A few facts about Autism Spectrum Disorder:

- Figures from the recent research indicate that one in every 160 births will result in a child with Autism Spectrum Disorder
- Out of every five people with ASD four will be male
- About one third of people with an ASD do not develop functional speech
- Approximately one third will develop epilepsy by the time they reach puberty
- ASD can co-exist with other disorders such as ADHD, Epilepsy Rett's Syndrome, Fragile X, Down Syndrome and Tuberous Sclerosis.
- Approximately 75% of people with autism also have an intellectual impairment.

Sensory processing difficulties are experienced by a large number of people with an ASD and a great deal has been written by more able autistic people such as Temple Grandin, Wendy Lawson, Donna Williams and Jim Sinclair. These difficulties/issues cannot always be seen and so, often what we see in relation to a situation is unusual behaviour that can sometimes escalate to a 'tantrum-like' episode. All five senses can be affected: hearing, sight, touch, taste and smell. (Although not all usually in the same individual.) Often the difficulties experienced by people with ASD fluctuate from day to day – hearing can be super-sensitive one day and not so sensitive the next, leaving those who parent, care, and work with children and people with ASD often wondering what is happening.

The following are examples of sensory issues that have been written by people with ASD:

Touch

Temple Grandin "I pulled away when people tried to hug

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me, because being touched sent an overwhelming tidal wave of stimulation through my body. Small itches and scratches that most people ignored were torture. A scratchy petticoat was like sandpaper rubbing my skin raw. Hair washing was also awful. When mother scrubbed my hair my scalp hurt. Church was a nightmare because the petticoats and other Sunday clothes itched and scratched. The good clothes felt differently than every day clothes. Whereas most people adapt to new clothes in a few minutes, it took me three or four days to adapt. Many behaviour problems in church could have been avoided by a few simple clothing modifications. Changing types of underwear is still a problem today. The reason I wore shorts during cold weather was because I could not tolerate the feeling of long pants against legs which had been bare all summer."

Smell and movement

Albert (13 Years)

"It feels funny to be autistic. Like riding a truck around really fast, riding through a whole house fast, excited. I smell something really strange, I ride my truck really fast and spin around."

Sound

Darren White (1987)

"I was frightened of the vacuum cleaner, the food mixer and the liquidiser because they sounded about five times as loud as they actually were. The bus started with a clap of thunder, the engine sounding almost four times as loud as normal and I had my hands in my ears for most of the journey. Another trick that my ears played was to change the volume of sounds around me. Sometimes when other kids spoke to me I could scarcely hear them and sometimes they sounded like bullets."

Sight

Darren White (1987)

"I used to hate small shops because my eyesight used to make them look as if they were even smaller than they actually were. I also remember one Christmas when I got a new bike for a present. It was yellow. I would not look at it. Extra red was added to the colour making it look orange, and it blurred upwards making it look like it was on fire."

Taste

Sean Barron (1992)

"I had a big problem with food. I liked to eat things that were bland and uncomplicated. My favourite foods were cereal – dry, with no milk – bread, pancakes, macaroni and spaghetti, potatoes and milk. Because these were the foods I ate early in life, I found them comforting and soothing. I didn't want to try anything new. I was supersensitive to the texture of food, and I had to touch everything with my fingers to see how it felt before I could put it in my mouth. I really hated it when food had things mixed with it, like noodles with vegetables or bread with fillings to make sandwiches. I could never, never put any of it into my mouth. I knew if I did I would get violently sick. Once when I was very small, I tried to eat a banana for my grandmother, but I couldn't do it. So from then on I refused to eat any of the other fruits. I wanted to eat things I was used to: the others were very threatening to me. When Mum tried to get me to eat something new I got very angry with her – I knew what I wanted!"

Multiple sensations causing stress

"Reality to an autistic person is a confusing, interacting mass of events, people, places, sounds and sights. There seems to be no clear boundaries, order or meaning to anything. A large part of my life is spent just trying to work out the pattern behind everything. Set routines, times, particular routes and rituals all help to get order into an unbearably chaotic life. Even when I want sometimes to take part in something, my brain just will not tell me how I should go about it and contrary to what people may think, it is possible for an autistic person to feel lonely and to love somebody."

Interests and obsessions

Many people with ASD have interests that sometimes become obsessions. Parents usually see these early in their child's life – an intense interest in Thomas the Tank Engine and Bob the Builder for example. These characters and programs are 'hits' because they are predictable, consistent and there is symmetry. Likewise many older people with ASD enjoy 'Star Trek' and in particular Mr Spock as he too is predictable with a face that doesn't show complex emotions that are so difficult to understand.

Many people with ASD who have interests make collections while that interest is 'en vogue.' Children can collect rocks, straws, pencils even the very unusual which can stretch friendships like seeking out toilet brushes when visiting . One person with ASD wrote:

"I also liked collecting the lids of tubes of Smarties. These

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were orange, green, blue, red and yellow and had a letter of the alphabet on. I had more orange ones and only a few blue ones and I never got all the letters of the alphabet. The only problem was that I wanted to take the lids off the tubes of Smarties when I was in a sweet shop so that I could see what the letter was underneath and this seemed to make other people angry."

People such as Dr Temple Grandin, a person with High Functioning Autism, who now has a doctorate in Animal Sciences and lectures at Colorado University had a strong interest in squeeze machines which occupied her time at home hand then in school on designs which eventually led her to her chosen career which has been enormously successful. In her books: "Emergence Labelled Autistic" and "Thinking In Pictures" she describes the teacher who took an interest in her interest/obsession which enabled her to pursue it as part of her education.

Interests can be used as a reward for completing tasks, to work on in 'free-time' and as a unit of work within the classroom. Reference to them will certainly attract the student's attention, and this will make him/her more receptive to instruction. They can also be used as reinforcers in a behaviour management program.

Communication

Approximately one third of people with ASD do not develop functional speech. Those who develop speech show marked difficulties in both receptive (the ability to understand the spoken word) and expressive (ability to use the spoken word accurately and appropriately) language. Less than 10% of children with ASD have language skills that equate to their chronological age. Some verbal children exhibit 'echolalia' which can be immediate or delayed, others have deviant language use and some talk about their topics of interests sometimes to the exclusion of everything else.

Wendy Lawson, an adult diagnosed with Asperger Syndrome when she was in her early forties termed a phrase at the National Biennial Autism Conference in Hobart in 1999 to describe the non-autistic people of the world as 'neuro-typicals' or NT's!

The world of NT's is language rich – the way we like it. However that is not the way the person with ASD likes it. We need to remember that communication is one of the areas that people on the spectrum have difficulty with. It is one of the criteria set down that is part of the assessment and diagnostic process.

What we know about communication in people with Autism Spectrum Disorder.

There is:

- Very literal interpretation of language
- Difficulty with expressive and receptive language
- A need for more time to process spoken language
- A poor auditory memory
- Difficulty understanding multiple instructions
- Pedantic, stilted expressive language
- Fixations on specific topics of language

We know from research that people with ASD are visual learners. Reading books written by able people on the spectrum such as Dr Temple Grandin and Wendy Lawson explain succinctly how well they learn when things are presented in a visual form. The world of neuro-typicals is full of language – both spoken and written.

From the research we know that people with ASD prefer

- Visual cues to aid learning and communication. These can be real objects, photos, Compic, Makaton signs or gestures. Cues give control, allow simple instructions to be followed, assist in the understanding of change, follow a sequence, have needs met, express feelings
- A structured environment provides routine, allowing responses to be successful and positive because they're less difficult to understand. They allow the person to predict, anticipate and see what is now and also what is next. It provides a means to manage change and set up for unpredictable events – visitors, cooking instead of walking. These assist to extend skills
- Short precise and positive instructions result in the best response as the person with ASD is more likely to understand and comply
- Individual instruction: don't assume group instruction is understood or focussed on by an individual. Instruction may need to be repeated on a one-to-one basis.

As functional and useful aides to communication **visual**

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schedules or timetables are extremely useful as they help the person cope with changes, reduce stress, increase independence, enable the following of routines and teaching new ones and enhance behaviour management.

How do we do them? Choose appropriate visuals to use. (They may include pictures, words or a combination of both.) Keep the timetable to an appropriate level depending on the student eg: whole week versus the whole day versus each session. Be consistent with the symbols you use, when you use it and how you use it.

Behaviour

What is behaviour?

The Concise Oxford Dictionary states that behaviour is: 'deportment, manners, way of conducting oneself' and the Macquarie Dictionary defines behaviour as: 'manner of behaving or acting.'

What is challenging?

The Concise Oxford Dictionary states that challenge is 'a demanding or difficult task', and the Macquarie Dictionary defines challenge as: 'something that makes demands upon one's abilities, endurance, etc.'

Do we see 'behaviour' as challenging because we don't necessarily know how best to 'deal' with the person and their way of behaving in what is a difficult situation for them.

With knowledge those working with children and people with ASD will have a more empathetic understanding of why the 'behaviour' is happening and handle the situation with skill. This implies appropriate management that respects both the person, having their needs uppermost in mind, and fosters an atmosphere of co-operation leading to desired outcomes.

To change behaviour, we need to understand why it is occurring and what is sustaining its continuation. We need to look beyond the surface behaviour to try and understand the purpose of the behaviour from the perspective of the person with Autism Spectrum Disorder. Often, to change behaviour, we have to modify what **we** do as well as the environments in which we interact and teach. There are a number of areas that affect behaviour.

Lack of self-awareness:

- Behaviour tends to be triggered by external stimuli and is not under the control of the person
- Limited sense of control may lead the person to restrict himself/herself to a limited range of familiar choices
- Poor self-awareness leads to a lack of choice in coping strategies, and a tendency to stick to one learned response

Sensory difficulties:

- Unusual sensory responses can result from sensory and perceptual difficulties in autism
- Being wary of social situations can be a result of sensory hypersensitivity to sound, sight, smell, texture or taste
- Sensory hypo-sensitivity can also be a problem, when people do not respond to sensory stimuli that could be harmful, eg: burning themselves

Rigidity:

- An insistence on sameness often leads to behavioural problems.
- Changes may lead to repetitive and stereotypic behaviours that may provide the desired sense of sameness and safety **and/or** may serve as a self-stimulatory behaviour providing comfort.

Lack of social awareness:

- Individuals with autism may have difficulty understanding other people's behaviour **and** predicting the likely actions of others
- The person who has autism may attempt to meet his/her needs by : walking through or over obstacles if necessary; grabbing or snatching at something, even if someone else has it at the time **or** having a tantrum if his needs are not met
- Basic social approaches may be misinterpreted, eg: biting a hand outstretched to help

Communication difficulties:

Difficulties understanding how to communicate may lead

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to frustration, anger and anxiety. Even if the person has speech it is not always used to communicate effectively. Does the person have a means of having his needs met? Does the person have any communication system other than his behaviour to say "No"? Have they been taught to use a communication system that allows them to say "I'm hungry", "I want a drink", "I need help"? Providing a communication system is of primary importance, not just in terms of behaviour management, but also in terms of the person's human needs and dignity.

Lack of self-help and play skills:

People with autism may lack the means of self-occupation and tend to withdraw into a narrow band of familiar behaviours.

There are also other factors to consider:

- **Illness** – always a consideration where there is an unexplained deterioration in behaviour, especially in people who are non-verbal, who cannot tell you about headaches, toothaches and other illnesses. However a person who is verbal often finds it extremely difficult locating their area of discomfort/pain. (A majority of people with an ASD have a high threshold of pain.)
- **Fatigue** – has the person slept well the night before? Does the behaviour occur at the same time each day? If so modifying the program so that the work can be done earlier can relieve stress and provide success.
- **Hunger**. Is there a pattern related to meal times? Does the person have a means of communicating their hunger or thirst? If the person has language they may not be able to initiate the conversation that tells us.
- **Complexity of the task** Has the person the skills to do the task? Have they been taught all the steps required to complete the task? Is the task too complex for them? Are they afraid of failure and the negative feedback that may go with it?
- **The environment** Is the environment overstimulating? Is it busy, noisy, intrusive, crowded (supermarkets, sports day etc)? It is unreasonable to expect the individual to spend long periods in these situations. Build tolerance from short periods to longer periods. With some

people it maybe best to avoid these situations altogether.

- **Fear of change**. Does the person have a visual system that tells him about change and the things that are going to happen next? We need to remember the person with ASD makes sense of the world through routines and depends heavily on them – both self created and imposed by others.. Without some method of preparing the person for change, in advance, the person may find change very stressful.
- **Duration of activity**. Does the person become agitated as the day progresses? Consider giving the person short planned, pro-active respite breaks. Build these breaks into his daily schedule. After an intense or busy period, plan down time when the person can have a calming time.
- **Under-stimulation**. Are the tasks the person is doing too simple? Is the person constantly having to repeat the same task with the same materials? Is the work motivating? Is there a system in place that allows the person to know what is expected, when the work is finished and how to go on to a new task?

When problem solving a behavioural issue, what do we need to do?

- Never look at behaviour in isolation
- What is the behaviour we are trying to deal with?
- How often does it occur?
- Is there a pattern to what causes the behaviour?
- What can **we** do to reduce the frequency of this behaviour?
- What can **we** do when the behaviour occurs?

Involving **all** the people who work with the particular person with ASD is vital in problem solving a behaviour issue. Everyone needs to have the same clear objectives, the same expectations, the same strategies and consistency at all times is vital.

What do we need to do to prevent the problem?

- Understand why the problem happens.

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- Structure the environment for prevention
- Provide a means of communication
- Structure social demands to the level of the person's ability to cope
- Set tasks at the person's level
- Match rewards and reinforcements to the person's interest and needs
- Allow for interests/obsessions
- Provide times for de-stressing

MOST IMPORTANTLY: does the person know what he has to do? (Often we tell people what NOT to do but not WHAT to do.) In the case of people with ASD they do not automatically know what is the required response.

Social stories are also very useful tools in helping a person with ASD understand what they are going to do, participate in or need to do in a social situation. The goal of the social story is increased understanding of the requirements of the given social situation, not just improved behaviour. The focus of social stories is that **they tell the person what needs to happen** and **not** on what shouldn't happen.

Behaviour is the communication of last resort for people unable to communicate their needs in any other way.

Ritualistic behaviours and routines

If we could imagine life with all the difficulties of a person with ASD we may begin to understand the function of 'interesting' behaviours which manifest themselves in routine, sometimes very elaborate. How does the person with ASD know what is going to happen now, in an hour, this afternoon, tonight, tomorrow.....? Not knowing information when it is important and affects our daily lives places many of us in a stressful situation. A great number of people with ASD live with stress and anxiety that very few of us can imagine. Ritualistic behaviours provide certainty and comfort in a world where very little is certain. They appear to be imposed so that life becomes more predictable and orderly, as novelty, chaos or uncertainty are intolerable.

"I loved to copy, create and order things. I loved our set of encyclopedias. They had letters and numbers on the side,

and I was always checking to make sure they were in order or putting them that way. I was making order out of chaos. Searching for categories did not stop with the encyclopedias. I would read the telephone directory, counting the number of Browns listed, or counting the number of variations on a particular name, or the rarity of others. I was exploring the concept of consistency. It may have seemed that my world was upside down, but I was looking to get a grip on consistency. The constant change of most things never seemed to give me any chance to prepare myself for them. Because of this I found pleasure and comfort in doing the same things over and over again." Donna Williams.

School-age children often respond favourably if their specific interest or obsession can be incorporated into a program. By doing this structure and routine are provided while allowing 'legitimate' time for the activity. Schedule boards can include these activities in the daily timetable so the child can see what is coming up and more able students through careful negotiation can incorporate them into their own routines without necessarily specifying a time.

How can we help people with Autism Spectrum Disorder?

- We can help people with ASD by recognising the difficulties they experience each and every day. We can recognise those things that cause stress and anxiety – it is within our 'power' to change some of these so there is less stress. People with ASD experience severe stress far more frequently than most people and are less able to deal with it effectively than most people.
- We can provide them with an appropriate communication system and examine how we communicate with them. (We often use far too many words).
- We can lessen the changes to timetables and provide a means of facilitating changes on schedule boards so that the person with ASD has prior warning. There will be times when this is just not possible, however it is important to substitute a preferred activity with another highly preferred activity.
- We can recognise the person's skills and interests and use these as a basis for their school program, work program or their recreation time. They can also be used as rewards instead of 'free time'

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which is difficult for people with ASD – how do they make a choice of what to do? Making choices are difficult.

- We can ensure that there is 'down time' to de-stress and do something that is relaxing and enjoyable to the person, **not** what we think is relaxing and enjoyable. (Using the library or computer at lunch time instead of going outside to play.)

Conclusion

I don't believe we should accept that the behaviours of people with Autism Spectrum Disorder are challenging. The primary responsibility rests with us 'neuro-typicals' because we can understand how other people feel. That we don't, won't or can't is a reflection on our ability to walk halfway across the bridge that divides our world from the world of Autism Spectrum Disorder.

Understanding Autism Spectrum Disorder and the difficulties it presents each individual with the disorder is paramount in providing a setting that allows the child/person to function to the best of his/her abilities. This will ensure that the 'challenging behaviours' are rarely a challenge, although at times they will be difficult. We as 'neuro-typicals' need to ensure we understand our friends with ASD and the difficulty they have living in our neuro-typical world. There is a choice.

AND TO END.....

The following piece was written by Jim Sinclair, a man with an Autism Spectrum Disorder who lives in the US.

"But my personhood is intact. My selfhood is undamaged. I find value and meaning in life, and I have no wish to be cured of being myself. Grant me the dignity of meeting me on my own terms....Recognise that we are equally alien to each other, that my ways of being are not merely damaged versions of yours. Question your assumptions. Define your terms. Work with me to build bridges between us."

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Premier's Disability Advisory Council

Autism Tasmania's President, Penny Cromarty has been appointed to the Premier's Disability Advisory Council (PDAC). The Council was formed in February this year, and consists of eleven community members appointed by the Premier. They include people with a disability, parents of people with a disability, a service provider representative body, people experienced in the welfare of people with a disability and people who have demonstrated an interest in disability issues.

The PDAC will work with the Tasmanian Government and the broader community to promote inclusiveness, enhance community participation and reduce barriers for people with a disability.

The following principles, taken from the Disability Framework for Action will underpin the work of the Council:

- *Equity:* People with disability have the same rights as other citizens and equal opportunity to participate in the social, cultural, economic and political life of our community and to access the structures, processes and resources to realize these opportunities.
- *Inclusiveness:* Mainstream programs, services and facilities should be available and accessible to people with disability.
- *Access:* Ensure access to specialist services that are appropriate to the needs of individuals.
- *Autonomy:* People with disability should be free to make or influence the decisions and choices that affect their lives.
- *Recognition of the contribution of people with disability:* The knowledge and life experience of people with disability, and the contribution that they make to society should be acknowledged and valued, including in

Government policy.

- *Non-discrimination:* All people have the right to live their lives free of discrimination.
- *Prioritising Resources:* Resources should be targeted to areas in which they can make the greatest difference in the lives of people with disability. Priority should be given to those in greatest need, particularly those with severe or profound disability.

The Council will provide a forum for advice on the views and experience of people with disability, their families, carers and advocates. It will also provide advice to the Government on Whole-of-Government disability policy, planning and programs, and assist in monitoring the implementation of the Disability framework for Action. It will provide awareness and education across all sectors of Government and the community in regard to the needs of all people with disabilities, their families and carers.

The PDAC will be chaired by the Premier and will include the Minister with portfolio responsibility for disability, Minister Lara Giddings, and the Minister for Community Development, Minister Michelle O'Byrne. The non-Government members are appointed as individuals and not as representatives of particular organizations.

Congratulations Penny on your appointment to the PDAC. Penny has been appointed to the PDAC as a parent of an adult with disability, not as a representative of Autism Tasmania. However Penny was previously a member of the Ministerial Advisory Council where she worked quietly and effectively to place autism on the political agenda. Ed.

Child Development Units

The Department of Health and Human Services has two Child Development Units (CDUs) across North and North West Tasmania.

The CDUs offer families a detailed assessment for below school age children where there are concerns about the child's development in more than one area.

For example, concerns could be in motor skills and speech, or general learning skills and emotional/behavioural adjustment.

Staff involved in the assessment can include psychology, occupational therapy, speech pathology and social work specialists.

This range of professional skills enables CDUs to provide the team assessments recommended when considering diagnoses of developmental disorders such as autism. Through 2006/07 some staff have also now had additional training (through Monash University and Western Psychological Services, USA) in using the Autism Diagnostic Observation Schedule (ADOS) and the Autism Diagnostic Interview- Revised (ADI-R).

CDUs work with families ensuring the family is central in determining how the assessment occurs and what steps they take as a result, such as referrals to other specialists or to support services. The family will be given a written report about their child's assessment.

Families in the North can access ongoing social work support, which may include help in managing their child's behaviour.

Often CDU involvement with a family is intense but short-term.

The Child Development Units work closely with other intervention services such as Early Learning Tasmania, St. Giles Therapy Services and other regional therapy services, so children and families can get help quickly when needed.

You can contact the Child Development Units at:

**35 Mace Street, Burnie 7320. Phone 6434 6201
or**

**13 Mulgrave Street, Launceston 7250. Phone
6336 2134**

(for information go to the service directory at www.dhhs.tas.gov.au)

Families in the South may be able to access assessments for their preschool aged child through Calvary Children's Developmental Therapy Services, Tower Road, New Town. Phone 6238 1801.

Positive Sayings

'There is not enough darkness in all the world to put out the light of even one small candle'
- Robert Alden

'We worry about what a child will become tomorrow, yet we forget that he is someone today' - Stacia Tauscher

'You can learn many things from children. How much patience you have for instance' -
Franklin P. Jones

'A characteristic of the normal child is he doesn't act that way very often' - Author
Unknown

'Shared joy is a double joy: shared sorrow is half a sorrow' - Author Unknown

Book review: Succeeding with Interventions for Asperger Syndrome Adolescents.

A Guide to Communication and Socialisation in Interaction Therapy by Harpur J. Lawlor M. & Fitzgerald M. (Kingsley publishing)

The usefulness of this guide extends well beyond adolescence. There is the most recent thinking on ASD and Asperger's in particular, the deficits and diagnostic characteristics, concluding that there is no simple explanation for AS occurrence or its symptoms. Many manifestations are still being uncovered and it does not have a full medical explanation. They accept that the AS person's perception of other people's behaviours is different; what is obvious to others is not so to someone with AS. The strengths of AS, such as perseverance and obsessions are opportunities for social interaction.

The fundamental puzzle of AS is 'how can people of normal to superior intelligence with good verbal ability fail to learn even a small amount of everyday social conventions? It is helpful to see in print that the apparent normality of AS people through casual encounters can be entirely misleading. The social impairments can be profoundly subtle, but intervention is necessary to achieve social competence. This apparent 'normality' places added pressure on AS children to fit in and a lack of understanding by neuro-typical others when they do not fit in.

AS people often require a justification for a particular rule or statement before they will accept it; they will often ask "why do we need to do this anyway/I can't be bothered talking to them?"

The right response is not to say that everyone else agrees or to dismiss their question, but to avoid conflict and reply calmly with an informative statement. Vulnerability to ridicule and social exclusion is a high risk due to difficulty understanding others and non-verbal communication. They do not have the protection of friends, are anxious and are avoided by non-bullying peers also. As people are seen

as socially naïve and they find the world of social interaction confusing, unpredictable, frustrating and frightening. Their most frequent emotions are fear and anxiety and changes in routine create stress. Due to past rejection, AS may feel more secure giving a hostile response when anxious. It is helpful to ignore provocation, remind about constructive behaviour and respond with neutral statements "I see your view, but there is another as well." Displays of social negativity often mask social distress and emotional confusion. They need to imagine things differently.

Organisation and planning are challenges for AS people and the co-occurrence of anxiety, depression, ADHD, OCD, present huge barriers to education and independence. Depression and motivational torpor are common, as are psychiatric and emotional problems. AS peoples' needs can be judged as less important and that they are just being intentionally hostile, indifferent or dismissive (when judged against their typical peers) which acts against them getting the necessary assistance in schools. The attribution of intentionality should always be the last explanation for the behaviour of those with AS.

It recognises that parents can be sceptical of intervention due to previous failure and rejection in social settings. They may have been made feel culpable for their child's deficits through others' blaming them, which serves to socially isolate the family further.

The impact of AS on adolescence can include ridicule, social exclusion, lack of peer support and low self-esteem. They have difficulty with social perception and perspective taking, appropriate social responding, emotion regulation (e.g. anxiety and anger management), interpersonal problem-solving. But there is hope; many successfully go to further education and find employment.

Any social skills training must recognise the different orientation of AS people towards friends and company.

Two other factors which influence social skills training are the need for concrete explanations for adopting certain thinking and skills and the depressive or unmotivated outlook of many adolescents with AS. This training is within a group setting using role-play, group discussion, video modelling, relaxation to manage anxiety and planning for change. The aim is not to produce a 'typical' person, but to improve aspects of the AS perspective and values the involvement of the family. However, the genetic basis of ASD implies that many parents will have AS traits, largely unbeknown to them, which can limit their contribution.

The authors discuss what to consider when forming a group and what themes to focus on, such as initiating and responding in conversation, coping with bullying, avoiding giving offence, judging intentions, impulse control, empathy for others and recognising cues for turn taking and not interrupting. The predictable structure of explicit group rules and the creation of a secure environment, reduces anxiety and increases the likelihood of relaxation and openness to learning. The authors exhort the need to use positive constructive feedback with ASD, especially by parents. In their daily

lives, AS people receive little positive affirmation; this group may be the only place this occurs. The group contrasts their behaviours which got them into trouble, with those that brought respect and satisfaction, amplifying the latter and using the strength of the AS mindset of clear logical explanations of the impact of behaviours.

Friendship will always be a painful subject for AS adolescents.

The goal is to change the AS mindset but still allow them to be themselves. While parents will have limited opportunity to teach social skills, they must be kept involved in the intervention program. They will often be demoralised from meeting the demands of having a child with AS. They become ground down by the impact of their child's social difficulties and may face the added pressure of marital stress through a parent having AS.

The session outlines are intended to be adapted by the group leader. They conclude that AS adolescents are intriguing but sadly misunderstood young people, who will always respond to concrete thinking, facts and logic.

By Di Hamilton

Association for Children with Disability.

Win a free Autism Tas. Membership for 2008!

Included in this mailing is our annual Gold Coin Fundraiser.

Many members have participated in this activity over the past few years and some have earned themselves a free membership for the next calendar year.

**This year, we will be awarding free memberships
or Seminar registrations for next year.**

**So encourage your relatives, friends and workmates to donate a gold coin or two
to support the Family Support Service of Autism Tasmania.**

New Books for the Autism Tasmania Library.

Sometimes My Brother: Helping Kids Understand Autism Through A Sibling's Eyes by Angie Healy.

In this book three year-old Foster explains his perspective of his older brother, Gavin who has autism. 'This lovely picture book shows readers the challenges the boys face and the obstacles they overturn. Vibrant photographs bring you right into their living room, school and playground, adding an essential element of reality to the story. Foster's innocent approach is perfect for teaching others what autism is all about, and for letting other siblings of children with autism know that they are not alone. Angie Healy, the boys' mother, provides a how-to section at the end so families can create their own personalised books.'

This is a wonderful book and is very suitable for younger children as well as older family members as it explains autism extremely well.

Ian's Walk: A Story about Autism by Laurie Lears.

This book is written from the perspective of a sister of a little brother, Ian who has autism. It is an American book, however apart from the word 'diner' there is little difference to any family's experiences.

'Julie can't wait to go to the park. But she's not sure she wants to take her little brother, Ian, who has autism. Ian does things differently. At the local café, he doesn't care about the sandwiches and ice cream. Instead, he wants to watch the ceiling fan turn slowly. At the park, he doesn't like the tickle of a soft feather, but he loves to lie down and press his cheek against the hard footpath. It's hard for Julie to understand Ian. BUT when he gets lost at the park, Julie discovers that seeing the world differently – through Ian's eyes – is the best way to find him.'

When My Worries Get Too Big: A Relaxation Book for Children Who Live with Anxiety by Kari Dunn Buron.

This book is designed for both parents and teachers. In the foreword by Brenda Smith Myles, Ph D. she says: *When My Worries Get Too Big* is a wonderful book. It is a simple-to-use strategy that can help children and youth be successful. Children who use this book will find themselves relaxed and ready to work or play. In Kari's (the author) words, children with anxiety and behaviour regulation will realise that "They are awesome and in control!"

Teachers and parents can use this book to help children identify their behaviour and can remember things they can do if their worries get too big. *When My Worries Get Too Big* has great drawings that appeal to most children who would use this book with a parent or teacher.

Ten Things Your Student with Autism Wishes You Knew by Ellen Notbohm.

Parents' are their child's first teacher and this is a book for the teacher in all of us. In this book by Ellen Notbohm, also author of *Ten Things Every Child with Autism Wishes You Knew*, the unique perspective of a child's voice is back to help us understand the thinking patterns that guide their actions, shapes an environment conducive to their learning style, and communicate with them in meaningful ways. *Ten Things Your Student with Autism Wishes You Knew* affirms that autism imposes no inherent upper limits on achievement, that both teacher and child 'can do it.' It's the game plan every educator, parent, or family members needs to make the most of every 'teaching moment' in the life of the children we love.



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
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of the office of
Michael Ferguson MHR Bass

Autism Tasmania Support Groups

South

Hobart: meet on the second Thursday evening of every month at Tascare, 231 Main Rd. Moonah, starting at 7.30pm, there are various topics and guest speakers.

Cygnnet/Huonville: meetings as requested by parents.

North

Launceston: no set days but notices are sent out – various topics and guest speakers.

Exeter/Lilydale: meet on the last Friday of each month. This group alternates between Tresca in Exeter and a Lilydale venue.

NW and East Coasts

Burnie: no set days but notices are sent out – various topics and guest speakers.

Smithton: meet each month at the Rural Health Centre in Smithton. The day for these meetings is currently being re-negotiated

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

East Coast

Scamander/St Helens: the group meet at least once a term usually at Scamander. Notices are sent out to those in the area.

Adult Asperger Support Group:

This group meet on the last Sunday in the month at Tascare, 231 Main Rd, Moonah beginning at 2pm. The focus and topics of the get togethers are decided by the group. Notices are sent out prior to the meeting.

Several parent groups meet around the state. All enquiries can be made to Rose Clark on 0407 320 048 or 6423 2288.

A 'travelling library' is available to members of Autism Tasmania who attend these meetings. Books can be borrowed and returned a month later.