



# AUTISM NEWS

Newsletter of Autism Tasmania Inc.

*Postal Address*

P.O. Box 1552  
Launceston Tasmania 7250  
Australia

*Phone* 03 6343 2308

*Fax* 03 6343 2308

Edition 21  
December 1997

INSIDE THIS ISSUE

## ASPERGER SYNDROME

How Do You Share The News

What's in a Name - Reflections on Adult Diagnosis

Social Skills - Strategies for Teaching

Personal Accounts

*Printed on quality paper supplied by*  
**Australian Paper (Tasmania)**

## *Autism Tasmania Committee*

<b>President</b>	Rose Clark	6423 1086
<b>Vice President</b>	Jenny Vince	6273 5139 (work)
<b>Secretary</b>	Mark Ward	6343 2308
<b>Treasurer</b>	<span style="font-size: 2em; vertical-align: middle;">{</span> Rosanne Lay ✕	6244 2540 ✕
<b>Committee Members</b>	<span style="font-size: 2em; vertical-align: middle;">}</span> Lisa Minchin ✕	6223 2317 ✕
	Liz Maddern	6435 2021 (work)
	Julie Fyfe	6362 3189

### *From the President*

After attending the New Zealand conference, speaking with a variety of people and seeing some of what is happening in that country, I returned knowing we are working hard to inform parents and professionals connected with Autism Spectrum Disorder. One of the items that keeps recurring on our agenda is assessment and diagnosis. As parents, we know that the earlier intervention occurs, the better life can be for both child and family.

Recently, some disturbing information has come to light. Children who have previously been assessed and diagnosed by a specialist professional as having Autism Spectrum Disorder have been reassessed by another service and their diagnosis changed to Intellectual Impairment. The reason for the change in diagnosis is unclear. As noted international practitioner Dr Lorna Wing\* writes, "the question in diagnosis is not whether the child has autism or an intellectual disability but is he autistic and what is his level of intellectual function?"

As research shows, approximately 75% of people with Autism Spectrum Disorder have some level of intellectual impairment. The dilemma facing parents is that the difference in diagnostic decision will determine whether their child has a chance to receive the type of help required. The triad of impairments - lack of social interaction, verbal and non-verbal communication and adaptive behaviour - mean that children with Autism Spectrum Disorder require quite different help and learning environment to children with solely an intellectual disability, or for that matter, other disabilities.

A more serious implication for the future is that incorrect diagnosis, for whatever reason, distorts the number of people presenting with Autism Spectrum

Disorder and in turn, potentially affects the resources and types of services available in the community. While the situation for parents in these circumstances remains acute, the fact that these problems have arisen, reinforces the need for education and information on Autism Spectrum Disorder and why it is different. Autism Tasmania will continue to work towards providing quality seminars and speakers for both parents and professionals. In 1998, both Louise Ulliana and Tony Attwood will be presenting seminars/workshops for us.

As the Christmas break approaches and we brace ourselves for the occasional outburst from our children as their routine is broken for holidays, I remind you to look in last year's December newsletter for some handy holiday "survival" hints. As this is our last issue before Christmas, from all of us on the Committee, I wish everyone a happy and safe festive season and holiday break. Please read all your newsletter and see how you can make a contribution to our March issue.

*\*"Autistic Children - A guide for parents and professionals" (1985, 2nd Edition, New York, Brunner/Mazel)*

*Rose Clark*

### *New Zealand Conference 24th-26th October 1997*

I'm writing this directly on my return from Wellington after attending the first New Zealand Autism Conference. Over 500 delegates attended, including 30 from Australia. There were two keynote speakers - Dr Temple Grandin and Dr Luke Tsai, both from the USA - and two supporting speakers - Dr Tony Attwood from Australia and Mr Richard Mills from the UK. The three day conference presented a great deal of information,

some new, some thought provoking and some controversial.

Dr Temple Grandin opened and closed the conference with papers addressing the transition from school to work and her own experiences with visual thinking sensory problems and communication difficulties. From the reaction of delegates and comments, these presentations were the highlights of the three days. Her talks were honest and forthright, she spoke a great deal about her childhood, in particular her mother and the types of "early intervention" that occurred in her younger years.

One of the recurring themes in her talks was to make the most of the autistic person's strong points and not concentrate on the deficits. During her school years, Temple Grandin had one very supportive teacher who encouraged her to follow her particular obsession. This led to her establishing a successful international career in a very specific field - animal behaviour and the design of livestock handling equipment.

Dr Luke Tsai is a Professor of Child Psychiatry and Paediatrics from the United States, who presented three papers, dealing variously with the issue of whether high functioning autism and Asperger's Syndrome are the same or separate disorders; effective interventions for Asperger's Syndrome; and identification, education and treatment of autism.

Dr Tony Attwood from Brisbane spoke particularly about Asperger's Syndrome and ways of improving social behaviours; he also conducted a question and answer session on coping with challenging behaviours. As in past experiences, Tony's presentations were interesting, lively and pitched so all delegates could get a better understanding of the disorder. Tony has just released a new book, "Asperger's Syndrome - A Guide for Parents and Professionals". Autism Tasmania has ordered copies for our libraries.

A full list of Conference papers and presenters is included in this issue. If you want a copy of a specific paper or have particular questions, please contact Jenny Vince (03 6273 5139) or Rose Clark (03 6423 1086).

From a personal point of view, the highlight was my

meeting with Temple Grandin. I asked her to autograph my copy of her latest book, "Thinking in Pictures". She did so graciously and invited me to have dinner with her that evening. Vicki Bitsika, Margaret Kyrkou and I spent five hours listening to her life experiences and discussing opinions on a wide variety of subjects. It was a wonderful opportunity and most enjoyable evening.

*Rose Clark*

P.S. Autism Tasmania has ordered 3 copies of Dr Temple Grandin's book, "Thinking in Pictures", for our libraries.

### *About This Newsletter*

Our membership includes many members who have an interest in Asperger's Syndrome. In this issue we have compiled a number of articles which describe the syndrome and offer practical strategies which may help. We hope they are of interest to you. Please forward any contributions for our March newsletter to PO Box 1552, Launceston 7250 by the 6th February 1998.

### *Advance Notice - 1998 Seminars*

**March** - Dr Tony Attwood returns for 2 seminars run by Autism Tasmania. Tony has 25 years experience as a clinical psychologist specialising in Asperger's Syndrome and is well known in Tasmania from his previous visits.

**May** - Louise Ulliana will speak in Tasmania as part of National Autism Awareness Week. Louise, who is a speech pathologist and principal of Wetherill Park School in NSW, has recently presented papers and workshops at both the National Conference in Leura and the recent New Zealand Autism Conference.

### *Fundraising*

The Island Produce Fudge has been a really worthwhile fundraiser; so good that we've extended the deadline. If you want to place an initial order or increase your existing order, please ring Lisa Minchin on 6223 2317.

## FEATURE ARTICLES

### HOW DO YOU SHARE THE NEWS

by Dr Tony Attwood

*Written by Dr Tony Attwood, Clinical Psychologist, Msc, Phd, MAPS, AFBPsS. This article has been reprinted from the Fall '96 issue of the "Morning News" newsletter, edited by Carol Gray and published by Jenison Public Schools, Michigan, USA. It is reprinted with permission.*

Parents often ask whom they should inform about the diagnosis of Asperger Syndrome, how and when. The teacher and school authorities will certainly benefit from this information, as they can obtain access to resources and strategies to help the child. Should the other children in the class be informed? The answer will vary according to each child and their circumstances. For some it may help if the diagnosis becomes public knowledge, while for others it may be preferable that they are not distinguished from other children. There have been instances when the term Asperger Syndrome has become a derogatory term to tease the child, with the name changed to "Asparagus" Syndrome or "Hamburger" Syndrome. The author adopts the principle of - who needs to know? If not then exercise discretion with such confidential information.

How do we tell their brothers and sisters? They will probably overhear conversations and somehow learn of the diagnosis. If they have a level of maturity to understand the nature of the syndrome, then they should be informed. Fortunately there is now some literature on how to inform siblings, and parent support groups have organised activities just for siblings. These are usually co-ordinated by an adult who is the brother or sister of someone with Asperger Syndrome. The sessions enable siblings to share and discuss their feelings, learn ideas to cope with specific situations such as the response of their friends when they visit, and that feelings of embarrassment or rivalry are quite natural. They may feel they have an extra responsibility for them, especially at school, be confused as to why their parents are so concerned, wonder if their brother or sister will get better, and how they can help.

When do you inform the child that they have Asperger syndrome? There is no simple answer. Very young children will not have the maturity to understand the concepts. Older children may be extremely sensitive to any suggestion they are different. Their vehement denial of any inadequacy in social abilities is more an attempt to convince themselves than others. The answer may be to tell the child when they are emotionally able to cope with the information and want to know why they have difficulties in situations that other children find so easy. Sometimes this should be undertaken by parents, sometimes by professionals.

Carol Gray has designed a worksheet entitled "Pictures of Me", which can be used to introduce the child to their diagnosis. The worksheet is completed by the child, their parents and a professional, and involves a very professional attitude to the syndrome. The activities focus on the person's talents and abilities.

The author has found that their qualities of personality include being honest, loyal, reliable, forthright and having a strong moral code and sense of justice. Their cognitive qualities include an exceptional memory, enthusiasm and knowledge about their special interest, an original way of thinking, good imagination and remarkable ability to think in pictures. These qualities are not unique to the syndrome but are enhanced by it.

People with Asperger syndrome have many positive qualities in their abilities and personality. There are scientists and artists who have Asperger Syndrome who have used those qualities for great achievement. It is not a condition to be ashamed of, but one to express with pride. It is also important to explain that the person will improve their abilities and that they can achieve their goals in life. It may take some time, and Tom Allen described himself as like a turtle - developing small steps that eventually help win the race. Others have considered the analogy of climbing a mountain, again using small steps, but ultimately reaching the top. Better late than never!

Teachers can help outline the positive qualities of Asperger Syndrome by arranging an activity where the child, class or teacher prepare a story or play where the qualities of the person with Asperger Syndrome are an advantage. They are the hero. The

child can also examine the biographies of famous scientists and artists for indicators of whether they had the same attributes and personal experiences. A useful starting point are the biographies of Einstein, Mozart, Wittgenstein and Bartok. This could be a homework or library exercise. Hans Asperger had a very positive attitude towards those who have the syndrome. In one paper he wrote

*It seems that for success in science or art, a dash of autism is essential. For success the necessary ingredient may be an ability to turn away from the everyday world, from the simply practical, an ability to re-think a subject with originality so as to create in new, untrodden ways, with all abilities canalised into the one speciality. (p49)*

Great advances in science and art have been attributable to people with Asperger Syndrome.

Once the person knows they have this syndrome it can provide a sense of relief and understanding. This information may not have been acquired by a planned discussion with a parent or professional, but by reading literature on the subject. Christopher Gillberg describes, how a twelve year old entered his office and by chance found a leaflet for parents on the syndrome. The child then said,

*"This is something I've never heard anybody say a word about before. I think I'll call it A.S. for short." On reading the text aloud he soon remarked, as though in passing: "It seems I have A.S.! By golly, I do have A.S. Wait till my father hears about this. My parents might just have A.S. too, you know, my father in particular has all-absorbing interests. Now I can tell my classmates the reason why I pace the schoolyard briskly ten times up and down each break all the year round as I have A.S. And it will get my teacher off my back. If you have handicap condition they have to tolerate you." (P. 138)*

How do you explain Asperger Syndrome to other children. Carol Gray has written a program for school children called *The Sixth Sense*, ie the social sense. A series of activities highlights each sense and demonstrates how the sixth sense works. The students are then encouraged to imagine what it must be like have an impaired social sense and not fully understand the perceptual, cognitive and emotional perspective of others. For example, they are asked:

Would it be easy or difficult to take turns if you didn't know what others are thinking or how they would feel?

Would it be easy or difficult to talk to others about something they did?

Would it be easy or difficult to make friends?

Finally, the children are encouraged to identify how they might assist their classmate with Asperger Syndrome.

Sometimes it may be necessary to explain the nature of Asperger Syndrome to the parents of other children in the class. They can mistakenly believe the child is unusual due to some parental inadequacy, or the child is a potential danger to their son or daughter. The child's parents or a professional can address the school's Parents and Citizen's Association to allay their fears and to consider ways they can help the child and their family.

Asperger Syndrome is a developmental disorder and eventually the person learn to improve their ability to socialise, converse, understand the thoughts and feelings of others, and the accurate and subtle expression of their own feelings. The author uses the analogy of completing a jigsaw puzzle of thousands of pieces without a picture on the box. Over time, small, isolated sections of the puzzle are completed, but the overall "picture" is not apparent. Eventually there are sufficient "islands" of parts of the puzzle to recognise the full picture and all the pieces fall into place.

There has yet to be a study of the long term outcome of children with Asperger Syndrome. Professionals and service agencies tend to see adults who are having problems and who are conspicuous and this may lead to an overly pessimistic view of the long term outcome. The author has met many adults with Asperger Syndrome who have described how in their late twenties or thirties they eventually managed to intellectually grasp the mechanisms of social skills. from then on the only people who know of their condition are their family and those who know them intimately. Nevertheless, they can be very unusual characters. In this author's opinion, they are a bright thread in the rich tapestry of life. Our civilisation would be extremely dull and sterile if we did not have and treasure our people with Asperger Syndrome.

- i. Davies, J., *Able Autistic Children - Children with Asperger Syndrome: a booklet for Brothers and Sisters*, Child Development Research Unit, University of Nottingham, 1994 (Copies held in the Autism Victoria library).
- ii. Copies are available from Autism Victoria - Carol Gray has given them permission to reproduce the worksheet for private use.
- iii. Asperger, H. "Problems of Infantile Autism" *Communication*, Journal of the National Autistic Society, London, 1979.
- iv. Gillberg, C., "Clinical and neurobiological aspects of Asperger Syndrome in six family studies", in *Autism and Asperger Syndrome*, U. Frith (ed), Cambridge University Press, Cambridge, 1991.
- v. Gray, C., *The Sixth Sense*. In *Taming the Recess Jungle*, Future Horizons, Arlington, 1993.

## WHAT'S IN A NAME Reflections on Adult Diagnosis

by Rachel Evans

*Rachel is a former member of the committee of Autism Tasmania who is now working on the mainland. Rachel has forwarded the following article to Autism Tasmania and we thank her for her honesty, openness and extremely valuable contribution which will assist our many readers in their understanding of Asperger Syndrome.*

What is it like to be diagnosed with Asperger Syndrome as an adult and does being "labelled" really matter?

For me, being given a definite diagnosis a few months ago was both the end and beginning of a journey.

Other adults with autism/Asperger Syndrome (I am still undecided as to whether I believe these are the same disorders at different ends of a spectrum, or different but related disorders) talk about a lifetime of "knowing they were different", of not quite fitting in. My experience was perhaps a little different.

As a child I was quiet and shy, a listener more than a talker and an intensely private person but in general did not feel greatly different to my peers on the social front. I can look back now and see definite traces of Asperger Syndrome from as early as my preschool years but for me the most part, it really wasn't until I left the structure of school and home and had to make my way as an independent young adult that certain life patterns emerged and I began to look for answers.

When, in my first job I began working with children with autism spectrum disorder I found myself in awe

and I respect these quiet thinkers, at ease in their own world but struggling to relate to everyone else's. In discovering their characteristics I recognised mild traits in myself, but it was not until I attended the 1995 National Autism Conference (Brisbane) and learned more about Asperger Syndrome and autism in adults that I really started to question whether I presented with enough characteristics and to a significant degree to attract a diagnosis, or if I was merely at the autistic end of "normal".

My experience in working closely with parents of children with varying disorders and disabilities has taught me that for most people, being given 'a label' **does** make a difference - the indefinite becomes tangible, the abstract something concrete that can be more readily accepted, pursued and managed.

Certainly for me being diagnosed answered a great many questions but what struck me was the relief I felt that my own particular pattern of traits could be accounted for. In seeking answers about yourself there is always the fear that those you receive will be unwelcome. Being told I merely had mild autistic features as part of a normal profile would have been quite unsettling because the inference would have been that I was still basically like everyone else and so should cope with life in the same way. There was also the risk of attracting a diagnosis other than Asperger Syndrome, such as psychiatric disorder that unfortunately has a greater stigma attached by the wider community.

Having a diagnosis does not change who I am, but it has certainly enabled me to analyse my life in a more informed way, say goodbye to a lot of old ghosts, acknowledge my weaknesses and value my strengths. Most importantly it has altered my perspective to be more realistic about what I now expect from myself at work and in my personal life and to shape my life to accentuate strengths and minimise anxieties.

If you have a diagnosis:

- be kind to yourself - have realistic expectations and as much as you can set up your daily life for success
- give yourself lots of positive feedback - remind yourself of your strengths and the things you most value about yourself
- try not to resent your differences but value your

uniqueness

- as hard as it may be, try to accept that some things may always be difficult and require more conscious effort for you than for others rather than fighting them
- acknowledge the efforts of those around you to accept your differences
- be aware of activities that reduce daily anxieties (eg spending time alone) and allow yourself to indulge these
- break tasks up into small steps, rather than trying to deal with the whole picture
- think carefully about to whom you disclose your diagnosis and remember that disclosure is entirely your decision
- if you are comfortable doing so, share strategies you have found helpful with family, friends, workmates etc

If you are involved with someone with Asperger Syndrome, the most valuable help you can offer them is to:

- respect them as a thinking, feeling adult
- let them know that you value who they are
- be aware that being "high functioning" doesn't make the impact of disability any less
- acknowledge the acute awareness they have of their difficulties and the ongoing frustration this causes
- offer understanding and a patient ear when called upon but do not force these on the individual even though your intentions may be good
- not try to change them to be more like you but rather be flexible in your thinking and open to ideas about how you can help accommodate their differences
- respect their need for privacy and time spent alone

Living with Asperger Syndrome presents many ongoing challenges but is not a life sentence. People with Asperger Syndrome offer a unique view of the world and should be valued for what they can contribute.

## *What is Asperger Syndrome?*

*The following information is reprinted from "Asperger's Syndrome Parent Support Group" Leaflet, November 1996. The support group is affiliated with the Autistic Association of New South Wales.*

Asperger's Syndrome is a pervasive developmental disorder which falls within the Autism Spectrum. The main features of this disorder become obvious during early childhood and remain constant throughout life, although adaptation and degree of actual disability vary. It is very rarely recognised before the age of three and is more common in boys than in girls.

Some common features of Asperger's Syndrome children:

These children have excellent rote memory and absorb facts easily.

They generally perform well at Maths and Science.

They are generally anxious children who are unable to cope with any form of criticism or imperfection.

They can be the victims of teasing in a school environment, which may cause them to withdraw into isolated activities.

They find it difficult to generalise learned skills and appear to need to re-learn the procedure for each situation.

They often appear clumsy and may have an unusual gait and stance.

They are often seen as being odd and/or eccentric.

Language often appears good but may have limited content and poor social understanding.

Most attend normal primary and secondary schools.

While Asperger's Syndrome children have many of the features of the Syndrome in common, they may vary enormously in other ways especially in the areas of intelligence and temperament.

## DIFFICULTIES ARE OBSERVED IN THE FOLLOWING AREAS...

### *Communication*

Usually speaks at the age expected. A full command of grammar is usually acquired. Content of speech may be abnormal, tending to be pedantic and often centering on one or two favourite topics. Sometimes a word or phrase is repeated over and over in stereotyped fashion. Usually there is a comprehension deficit despite apparent, superior verbal skills. Non-verbal communication, both expressive and receptive is often impaired.

### *Social Interaction*

There tends to be impairment in two way social interaction due in the most part to an inability to

understand the rules governing social behaviour. A lack of empathy with others and little or no eye contact may be evident. Appears to be stuck at the egocentric stage of social and emotional development and therefore these people perceive the world almost exclusively from their own point of view.

### *Social Behaviour*

Social Behaviour is often naive and peculiar. They tend to become intensely attached to particular possessions. They engage in repetitive activities and are resistant to change, coping best when life is predictable. They are rigid and prefer structure and may concentrate exclusively on matters in which they are interested. May appear non-compliant as they have difficulty taking direction and coping with negative feedback.

### PROFILE

The typical person with Asperger's is a "loner" who never quite fits in because of eccentric behaviour, peculiar ways of speaking and a lack of social skills.

He or she may be interested in social relationships but lack the ability to understand and use the many rules governing social behaviour. He or she may try to make contact inappropriately, eg ignoring contextual cues or expressing inadequacy aggressively.

People with Asperger's Syndrome may graduate from regular schools and hold down jobs, but they are often disadvantaged by their odd behaviour and resistance to change.

They have difficulty establishing relationships and children often refuse to return to their homes to play with them.

Older children may over time withdraw from the uncomfortable interactions which characterised their early years and retreat into the safety of their family or even isolate themselves from their family.

They may feel rejected but do not understand how their behavioural responses contributed to their isolation.

### SOME ANECDOTES

He referred to a hole in his sock as a "temporary loss of knitting".

Yes he did want to go to school but he wished all the other children weren't there.

"Did you mop up the coffee you spilt on the carpet?"  
"No" she said, "it was too wet!"

## *Asperger's Syndrome - Social Skills*

Asperger's Syndrome students are socially "blind". The big problem is that they do not know how to behave even though they may know they are different and do not want to interact.

### Characteristics

- \* don't understand the rules of social behaviour
- \* don't understand the rules of games or the subtle changes
- \* can be very outspoken and tactless
- \* have a strong sense of justice, but see in terms of black and white
- \* lack the idea of personal space
- \* may dislike being touched
- \* don't interpret body language or facial expressions
- \* lack a sense of humour
- \* lack empathy ...don't understand own feelings let alone others
- \* may talk about inappropriate subjects
- \* may develop fixations on certain individuals
- \* misinterpret behaviours of peers
- \* have difficulty making friends ...often pair with similar student
- \* can appear naive and are vulnerable
- \* have poor conversational skills

### Strategies

You have to teach social skills in a practical way, constantly reinforcing the appropriate behaviour.

- \* debrief situations by discussing what he/she could have done
- \* physically act out situations
- \* teach conversational skills
- \* use written reminders to support proposed actions
- \* be aware in group activities that extra support is needed
- \* allow to observe (eg PE, Drama) until comfortable
- \* encourage self control by providing a "bolthole" or person (ie timeout as a reward or stress release)



- \*\* be very aware of how vulnerable the student is to peer pressure and being set up in class or playground
- \*\* remember that someone who doesn't have friends cannot "catch up" work from them if they are away or do not understand

\*\*\*VIP\*\*\*

Whilst it is important for the student to learn social skills required to exist safely and hopefully in a less stressful way in the world, lunchtime is not an ideal time to start! it is alright for the Asperger's student to be solitary after the effort of coping with a morning in school. It is often an idea to timetable the lunchbreak if the student finds it difficult to cope outside (eg library, computers), but don't make this an interactive session with other children.

### Conclusion

Asperger's Syndrome students need:

- \* consistency
- \* predicability
- \* a calm and controlled teacher
- \* an organised teacher
- \* a supportive teacher who encourages risk taking
- \* a teacher who encourages problem solving to promote independence
- \* a teacher who can help him learn that sometimes "Life's not fair, but that's ok, I can handle it".

Reprinted from *Asperger's Syndrome, Characteristics and classroom strategies, organisational skills, communication and social skills*, by Julia Smallwood, Irabina special Developmental School (Autism), February 1995.

### *Asperger Syndrome - A Personal Account*

*My name is Matthew Robinson. I am 17 years old and I would like to tell you about the problems I face every day which are related to having Asperger syndrome.*

Looking at me, a stranger in the street would see a perfectly normal teenager and would have no reason to believe that I lack the necessary social skills for coping with day-to-day living, skills that are essential for any social activity like going out with friends to

see a movie, going to a party or simply engaging in conversation.

For the majority of the population confronting people is a daily task which seems to come naturally. The act of walking into a room full of guests is one which most people find as easy as pie but one that I find nerve-wracking. Although you are carrying out what could be considered a relatively easy task, you don't know how the other guests will respond to you, you don't know what atmosphere you are entering and how to behave accordingly.

I attended a small Jewish primary school where I was one of 12 pupils. I cannot remember a lot about the general working day but I do remember that I was continually teased and made fun of and suffered from a total lack of self-confidence and anxiety particularly when communicating with other pupils.

I was an average student in class, made few friends and thought that at eleven I would be going on to a better school, to what I thought would be a whole new beginning. Indeed it was. I joined a secondary school with 1500 students and suffered six long years of isolation, loneliness, fear, anxiety, unhappiness and, ultimately, depression.

I do not wish to dwell too much on the experience I faced at secondary school but the problems I had that were related to Asperger syndrome hit me on a much wider scale.

I did not participate in class much, was teased, called names and generally disliked and taken advantage of. I felt different; indeed, I still do. As I look back at those school days, the fact that I had trouble communicating and behaving appropriately especially maintaining eye contact - is the reason why people treated me in this fashion.

If I had been aware at a much younger age that it was Asperger syndrome that was causing these problems, I might have been able to receive more practical help and be in a better position now. I have seen a behaviour therapist for the past 10 months who has managed to help me in such areas as assertiveness and social interaction and I currently attend a residential boarding school in Derbyshire and live with other students who have speech and language difficulties and a lack of social skills. The

school set up enables me to receive more help both academically and socially.

I would like to have a girlfriend, an active social life and be able to experience the same joys and happiness that most other teenagers seem to experience. Being a teenager can be harrowingly difficult at times and for those with Asperger syndrome it is even more so. If the majority of our society are socially skilled people then surely it is those people who should show understanding and sympathy rather than verbally abusing us.

They should try and understand the effect of their behaviour on people with Asperger syndrome and try to help us rather than attacking and damaging any confidence we have.

We are human beings and we deserve to be treated with respect and understanding, not with cruelty and aggression.

*Reprinted from Communication.....*

## *Learning Communication and Social Skills*

By Mo Austin

*Reprinted from Communication, Spring 1997,  
Published by the National Autistic Society, London.*

As the parent of a nine year old girl with Asperger syndrome and a support teacher to boot, I have been investigating ways of supporting my child in learning the communication and social skills which she finds so difficult. I have been persuaded to write about the strategies we've found successful in the hope that others may find them useful.

At home we all treat Sam in a very direct way. If she does something appropriate, like offering someone a sweet, or saying 'thank you' we praise her. If she hurts us by doing or not doing something, then we tell her how we feel. We cry if it seems appropriate, and indeed everything we do is an exaggerated response to her actions. Sam has difficulty reading facial expressions, and indeed responding with the correct 'face'. We play guessing games where she has to guess what feeling we are trying to express just by looking at our face. The

whole family join in, including her three siblings. Its fun and she's getting better at it!

One huge problem we've had is preparing Sam for new situations, so we role play a lot. I remember we all practised responding to the class register for three months every night before school until Sam was able to answer her name at the correct time with the appropriate volume and expression. The mistake we made was in not telling the school just how much effort it took to get Sam to do this one very simple task. We've learnt since.

Sam has big problems making friends. Until a year ago she opted out completely and ignored any situation which she couldn't respond to. Then she realised the importance of friendship, but didn't know what to do about it, so we structured situations to give her a headstart. She loves animals, so we persuaded the parents of her peer group to let her visit their animals. She'd go along to other people's houses quite happily after school and play with a dog or cat for two hours, and this gradually opened up opportunities for her to respond firstly to the adults and finally to her peer group.

Sam was making progress but she still couldn't initiate a conversation. We noticed however that Sam was much better at talking over the phone, where communication was entirely verbal, than face to face. Six months ago she made her first phone call to a previously primed classmate, and invited her over to play. She hasn't stopped since, though you have to be aware of 'phonespeak' responses which are taken literally. For example, 'I'll phone you back later on' would leave Sam sitting by the phone for the next four hours!

At school, choosing a partner would leave Sam standing alone so we suggested an artificial situation which was taken up by her excellent teacher. Now 'the people with the yellow bean bags' get to choose a partner first. Sam is now able to choose a partner, and the teacher is able to legitimately help her. We also told her teacher of the private non-verbal signals we have to check her understanding and mood. She has taken this on board and Sam loves the idea that she and her teacher have a communication system just for them. It makes her feel special.

Finally the difficult one. She is not allowed to have

a screaming tantrum. She is allowed to swear, shout and make angry faces but she has to communicate her frustration in some way. There is ultimate punishment which we've only had to use once in the last year since the system was initiated. We favour the 'subtle as a sledgehammer' approach, which I know, others find difficult to accept, but for us it works.

Sam still has major problems but we really feel she is making great progress. I'm a scientist, and within science teaching there is a theory that we can restructure people's ideas about science along more acceptable lines using a series of steps along the way. For example, if someone thinks that the sun goes 'to bed' at night we might get them to accept that the sun moves out of sight, but not that the Earth turns.

Indeed if we try to teach them the 'correct' answer immediately they will reject it - the leap is too difficult. We try the same for Sam. Each small step gets her closer to the 'ideal', but we accept she may never get there. If we try to do too much too soon, she never will.

*Mo Austin, support teacher and mother. If you would like to respond to Mo's article with any comments and further suggestions she would be happy to hear from you. Please send your comments to: Mo Austin, Budds Croft, Holcombe, Somerset BA3 5EF.*

## **Challenges in Mainstream Education**

by Ian Farquhar

*Reprinted from Communication, Spring 1997.*

*Published by The National Autistic Society, London*

The more able child or adolescent with Asperger syndrome often presents distinct challenges to parents and peer groups alike since they often manifest spectacular strengths alongside stark weaknesses.

Considered too high functioning for segregated special education, such children and young people are often placed in integrated settings. Their placements in integrated settings are potentially problematic, however, since the unusual combination of abilities and disabilities often puts them at risk for misunderstanding and misjudgment not only by

school personnel but by their classmates as well.

Bullying continues to be one of the biggest problems in schools and can lead to lost education, truancy, low self esteem and presents potential long term problems for social services, education and health. Latest estimates suggest that the problem is increasing.

Bullying can be based on anything that distinguishes one child from another including race, weight, appearance or academic ability. However, research suggests that some groups are especially vulnerable. Children with special educational needs who are integrated into mainstream school are considered three times more likely to be bullied than their peers (Childline, 1995).

Communication and social skills are not areas that individuals with Asperger syndrome take to instinctively as most people do. These individuals seem to lack awareness of this aspect of life. Those who don't use eye contact appropriately often miss out on reading the non-verbal communication signs of others' behaviour. They may at times use peripheral or top vision, which looks odd to others. Often the rules of proximity are misunderstood. Sometimes they are unable to judge who are their friends and who is merely an acquaintance or who is trying to take advantage of them. Play is often rigid, repetitive and unusual and they don't know how to ask to join play-groups.

At times they appear to lack imagination and creativity. Risk-taking and being able to see others perspective are often absent. The potential for teasing and bullying is, therefore, quite apparent.

### **Anti-bullying strategies**

Some schools and colleges have developed anti-bullying strategies which work extremely well. Others because of lack of resources have done little to address the problem in a positive way.

However, on the positive side, the more opportunities parents, teachers and other professionals involved in the field of autism and Asperger syndrome create for working together, the more opportunities there are to make our children's world a safer place.

*Written by Ian Farquhar, Development Officer, The*

*Scottish Society for Autistic Children, first printed in Summer 1996 issue of In Touch, SSAC's members' magazine.*

## From our Readers.....

*We welcome your contributions to this section of our newsletter, however the views expressed here are not necessarily those of Autism Tasmania.*

### Young Autism Support Tasmania

(Supporting families teaching ABA)

We were very fortunate at our last meeting to have Alison Jacob from the Education Department. Alison gave us the opportunity to ask questions regarding inclusion and funding among many other things. Many of our members have recently gone through the motions of applying to have their children placed on the category A register. So, there were many questions in reference to the funding issue. Alison was kind enough to offer to come back at a later date and perhaps bring Leigh Taylor with her to answer any equity issues. It's opportunities like these that enable us to gain a better understanding of inclusion and the funding process.

Martin Rush, a parent member of our group and a radiographer also spoke at our last meeting about a recent conference he attended in America on Magnetoencephalography or MEG for short. In brief, MEG is the reproduction or mapping of electrical activity in the brain. This technology has opened a new door to treating epilepsy and monitoring drug effectiveness. It seems that this process is more sensitive than MRI's and the benefits of which are yet untapped.

Our efforts over the last few weeks have focused on fund raising to assist in covering some of the expenses incurred to bring Jura Tender (Clinical Psychologist) to the state. We've had various members manning stalls at markets around Hobart and our recent and most successful effort was a Sausage Sizzle and Fun Day held at the Early Special Education Centre in Hobart on 2nd of November. The wet weather was a concern but the attendance was pleasing and a pleasant afternoon was had by all. The money we are raising will hopefully take some of the financial pressure off our families seeing Jura this visit which commenced on the 17th

November.

During Jura's visit an itinerary was discussed for 1998. Jura will be in Tasmania four times next year. An Asperger's Syndrome workshop was held on the 21st November at the Early Special Education Centre in Hobart and this was very well attended by both parents and professionals. Wishing everyone a safe and happy Christmas.

*Grace Talbot*

### Giant Steps Tasmania

Several changes have taken place on the Board after the recent AGM, and a completely new Executive elected - *Gerard Gelston*, Chairman; *Penny Cromarty*, Vice Chairman; *Ros Ward*, Secretary; *David Elmer*, Treasurer.

Financially, Giant Steps is at that very difficult part of the year when the gap in funds starts to bite and we are working hard to finish without a deficit. How successful we are will determine how we operate next year. Our main fundraising event, the Raffle and Baby Quest demonstrated that we have an event that can be developed into a very effective fundraiser and promotional activity - unfortunately, this first year it did not achieve the amount of money that we had anticipated, despite a lot of hard work.

Unfortunately, four staff - Andrew Hurst (Program Manager), Sarina Box (ADL Specialist), Meroe Robertson and Linda Faulkner (Therapy Assistants) are leaving at the end of term. Steps to replace them are already underway.

Several very positive things are happening and we remain confident of our future.

\* Bryce Courtenay, noted author, social commentator and previously advertising executive has agreed to become Giant Steps Tasmania's patron.

\* The review of the program by the education Department (as the preliminary to contract renewal) has been completed with very positive results. The Minister for Education has confirmed that consideration of the contract will be brought forward, before Christmas if possible and has suggested several ideas for overcoming enrolment problems and access to the program.

\* A strategic plan focusing on fundraising and

financial management has been sent to the Commonwealth as the next step in determining long term support.

\* Financial support from service clubs, businesses and individuals is increasing.

*Mick Clark*

## **Autism Tasmania.....An Internet Web Site? - John Wigg**

*John the parent of a young son with autism.*

Recently I have been searching at various libraries for information on autism. I was interested to note that Autism Tasmania's Victorian and South Australian counterparts have their own web sites as a way of advertising their existence to the world. Earlier this week I had the pleasure of a sneak preview of the Giant Steps Tasmania web page which Deloraine librarian is working on in co-operation with Andrew Hurst.

Peter tells me that web site home pages can be created from ordinary word processor files and data may also be scanned into the home page file using a flat bed scanner. A basic home page for Autism Tasmania could contain a reproduction of our basic information/membership application form as one page and a directory of office bearers and regional contact persons plus HTML links to other useful websites for people wanting information on autism spectrum disorders. Once the home page is set up the committee secretary could provide regular updates to Tasmania Online or whichever service provider Autism Tasmania chooses to use to create and maintain the website.

I am sure I am not the only parent who "surfs the net" for helpful information on autism. The internet presents Autism Tasmania with a window which can be opened to the whole world .. a handy advertising medium. Let's have feedback from other Autism Tasmania people on using the Internet as a billboard.

*Your comments can be sent to Autism Tasmania.*

## **LETTERS TO THE EDITOR**

### **Inclusion**

I read with interest the articles on inclusion in the

previous issue of Autism News - the view of the Autism Consultant, and the view of an educator in a special school. Regular schools versus special schools, should we include our children or should we segregate? I firmly held the belief for several years that we needed to segregate before we could integrate. This has proved to be very much the case for our family.

Our son, Michael is now eleven. He was diagnosed in 1991 (Melbourne) when knowledge of autism in Tasmania was scant. His education included a pre-school language unit, a stint at a regular school in kindergarten and prep, attempt and failure to move into a grade one, ultimately leading us to a special school where the children predominantly had physical disabilities, but the classes were small.

Michael began at Giant Steps in 1995 when the program commenced. He began an inclusion program earlier this year and now spends two days a week in a regular school with a full time aide. The remaining three days of the week are spent at Giant Steps.

Michael's entry into a grade five class at a small Catholic school in Launceston is the sixth school he had attended in his short life. Academically he is functioning at a lower level than the other students in the class, but he is now at the stage where he benefits from being around normal children, learning appropriate behaviours and responses in given situations. This was not the case three years earlier.

Michael is very much part of the class, the children are very caring of him, often fascinated by some of his ritualistic behaviours but not patronising. He has been invited to a birthday party, and to a "friends" house to "play" (We waited a long time!).

Why has Michael's inclusion worked so well? We chose a school that was extremely supportive; a school who saw Michael as a challenge and thought the experience would be good for their school; a small school and therefore a little more personal and a school where a friend of ours is the special education teacher. She did the groundwork in preparing the staff and children before Michael arrived, giving them information on autism and on Michael.

Moving from Giant Steps to the regular school meant Michael was able to access a full time aide from the centre, who was experienced in dealing with autism. This relieved any concerns parents had about him taking up too much of the teacher's time. The combination of these factors combined with the support the school received from Giant Steps made the transition very smooth and far more successful than we could ever have hoped for.

The support Michael receives in the classroom is vital. Michael's aide adapts the classroom program where necessary. To begin with she also spent recess and lunch time in the playground to assist him socially, negotiating "break" times with the classroom teacher. As Michael has progressed, the children have taken on more of a peer support role in the playground. Our aim is for him to spend some time in the regular school unaided.

We often hear that it is not appropriate for higher functioning children to be dependent upon an aide, after all we want them to be independent. Perhaps the system needs to be more flexible, allowing children access to greater aide time in the beginning, weaning out where appropriate.

Over the last seven years we have experienced all the options that are open to parents - special school, regular school, an autism specific program. Michael is not high functioning, but inclusion has been successful because the appropriate support has been available. Without it, placing Michael back in a regular school would not have been an option.

*Ros Ward*

## **Autism Register Centrally Funded/Category A**

*A question often asked by parents is how do children with autism in Tasmania receive category A status? The following information which has been supplied to us by Ms Leigh Taylor, Senior Superintendent Equity, DECCD, is distributed to all support services and schools..*

There is a small group of children for whom Autism creates highly significant educational implications. Eligibility for the Autism Register is determined on the basis of:

- \* a student demonstrated functional abilities, particularly in relation to DSM IV criteria and the associated educational implications (see page 16) and
- \* a confirmed diagnosis of Autism from (a) professional/s with expertise in this area.

It is recognised that Autism Spectrum Disorder forms a continuum from mild to severe and from low to high functioning. The social and functional implications and the educational impact of Autism varies depending on the relationship between these two dimensions. A diagnosis of Autism alone is therefore not sufficient to ensure eligibility for the Register. The register identifies students for whom the learning/educational implications resulting from Autism are the most severe.

Students with a diagnosis of Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS) or Asperger Syndrome are not eligible for the Register. A "high functioning" student with Autism, would by definition, not be eligible for the Register.

A **moderation committee** has been established to determine eligibility of students nominated for the Autism Register. The committee comprises:

- \* Margaret Ridgers (Manager, Macquarie District Support Service)
- \* Gail Vardy (Assistant Manager, State Support Service)
- \* Mary Leahy (Senior Guidance Officer, Barrington District)
- \* Lynne James (Acting Manager, State Support Service) Chairperson

The committee will meet twice each year to consider nominations for the register.

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

- \* Guidance/Psychologist's report including:
  - a social and developmental case history
  - a comprehensive cognitive or developmental assessment (eg Weschler Test, Griffiths, Merrill Palmer) including the assessment profile;
- \* Behavioural Observation - CARS completed by observation not report. This may be completed by a professional other than the guidance officer or psychologist;

- \* Educational report for all school age children outlining functional abilities and educational implications
- \* Speech pathology report
- \* Other documentation considered relevant to the nomination eg Medical/Paediatric report, occupation therapy report, parent report etc

Nominations for the Autism Register must be forwarded through, and endorsed by the Appropriate District Support Service Manager by dates which will be advised. District nominations will then be forwarded to the Committee. The results of the Committee's deliberations are returned via the District Service Manager.

Children exiting kindergarten who have been supported by Early Special Education Services are nominated via the State Co-ordinator for Early Special Education with appropriate advice to the relevant District Support Service Manager. These nominations from Early Special Education should be submitted in the second annual round of moderation. This provides maximum time to allow for, and assess, the very young child's development and educational participation prior to nomination for the register.

Placement on the Register does not guarantee any particular level of funding. It simply identifies students for Central rather than District funds. Students with Autism who are not eligible for the Autism Register can still receive support and advice from their District Support Service and the Statewide Autism Consultant. They may also receive funding from their District Special Education Committee. Queries regarding the register can be directed to The Manager, State Support Service on 6273 5138.

*Editors Note - Although placement on the Autism Register does not guarantee a particular level of funding in government schools, currently only children with Category A status are eligible to be funded by the Department to attend Giant Steps. Giant Steps has been working with the Minister for Education and the Department to enlarge the group of children able to access the program.*

## *Papers presented at the New Zealand Autism Conference*

### Author - Title

1. Temple Grandin - Making the Transition from the World of School to the World of Work
2. Luke Tsai - High Functioning Autism and Asperger Syndrome Disorder: Are they the same disorder or two different disorders?
3. W. Anderson, M. Brooks, J. Bruce, L. Hayes, U. Preston & D. Strugnell - A Team Approach to Assessment and Intervention: A Case Study
4. Celeste Littek - Playing for Inclusion: Cooperative Learning in Early Childhood
5. Temple Grandin - My Experiences with Visual Thinking Sensory Problems and Communication Difficulties
6. Louise Ulliana - Assessing Functional Comprehension Skills of Learners with Severe Communication Impairment
7. Jacqueline Roberts - Differential Diagnosis of High Functioning Autism /Asperger Syndrome and Developmental Language Disability
8. Richard Mills - Residential Options for Adults with Autism and Asperger Syndrome
9. Luke Tsai - Autism - Identification, Education & Treatment
10. A. Christie, S. Robertson - Katie - A Child with Autism
11. Tony Attwood - Social Behaviour
12. Richard Mills & Catherine Burkin - Prospects - A Supported Employment Scheme for Intellectually Able People with Asperger Syndrome
13. Jacqueline Roberts - Echolalia
14. Trevor Roberts - My Child Can't Play
15. Daphne Rickson - Reaching the Autistic Child with Music
16. Rod Hutchison - Developing Auditory Skills in the Classroom
17. Leonie Kershaw - Sexuality and Severe Autism - Out of the "Too Hard" Basket and into the "Can Do" File
18. Felicia Schmaman - Auditory Integration Training - What's in a Tune?
19. Tim Powell - Crisis Management in Autism
20. Luke Tsai - Asperger Syndrome: Effective Interventions
21. Trevor Clark - The Application of Savant/Splinter Skills in the Autistic population through Curriculum Design: A Longitudinal Multiple Replication Study
22. Bonny Le Grice - Judging the Effectiveness of a Treatment - A List of Criteria for Parents to use to evaluate a Child's Programme

The DSM IV criteria was forwarded to Autism Tasmania by DECCD in relation to the information on eligibility for the Category A Register (Autism).

*The Diagnostic and Statistical Manual of Mental Disorders IV (DSMIV) describes the following diagnostic criteria:*

A.

- (1) Qualitative impairment in social interaction as manifested by at least 2 of the following:
  - \* marked impairment in the use of multiple non-verbal behaviours such as eye to eye gaze, facial expression, body postures and gestures to regulate social interaction;
  - \* failure to develop peer relationships appropriate to developmental level
  - \* lack of spontaneous seeking to share enjoyment, interests or achievements with other people (eg by a lack of showing, bringing or pointing at objects);
  - \* lack of social reciprocity
- (2) Qualitative impairments in communication as manifested by at least one of the following:
  - \* delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime);
  - \* in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others;
  - \* stereotyped and repetitive use of language or idiosyncratic language;
  - \* lack of varied, spontaneous make believe play or social imitative play appropriate to developmental level.
- (3) Restricted repetitive and stereotyped patterns of behaviour, interests and activities, as manifested by at least one of the following:
  - \* encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus;
  - \* apparently inflexible adherence to specific, non-functional routines or rituals;
  - \* stereotyped and repetitive motor mannerisms (eg hand or finger flapping or twisting, or complex whole body movements);
  - \* persisting preoccupation with parts of objects.

B.

Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

C.

The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.