



From the Editor

The goal of the Editorial Committee is to select interesting and up-to-date information about Autism for our members. For this issue of the Newsletter, a number of articles ranging from research into ASD to papers presented at the recent Autism Tasmania State Conference has been chosen. Highlights of this edition are the stories from three people who are themselves on the Autism Spectrum; plus Rose Clark's account of her recent experience at the Autism Conference in Brunei!

I think most would agree that our Inaugural Autism State Conference in June was a resounding success! Members of the Organising Committee were both delighted and surprised by the number of delegates attending and the interest shown in the presentations, from both local and interstate speakers. Interestingly, the breakdown of delegates was fairly evenly divided between families and professionals.

When we consider this in the context of the research about the Californian Autism "epidemic" – it is not surprising that more and more families are being affected by Autism. Parents, carers and extended families have a need for as much information about Autism as they can handle. This is one of the main reason why Autism Tasmania has created the position of Family Support Co-ordinator

It was also very gratifying to see Teachers, Therapists, Health Professionals and Respite

Carers showing their need to gain practical knowledge and skills in order to better support individuals on the spectrum. I know that people are already looking forward to our next Conference!

At the Annual General Meeting in Launceston on August 17th, there will be several opportunities, both formal and informal, for YOU to have your say about the priorities that Autism Tasmania sets and works on for the coming year. The Committee really wants to hear from you and is looking forward to seeing you there!

Cheryl Scott (Editor)

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Autism and Digestive Difficulties – A personal experience

Many individuals with autism experience gastrointestinal disturbances and suffer from auto-immune disorders. Dietary interventions and nutritional supplements are often used to ameliorate the symptoms of these problems and to improve the quality of life of the individual concerned.

The presentation provides a brief overview of the experiences of one person by:

- *Describing the sources of information and supports available.*
- *Describing the reasons for the use of these interventions.*
- *Providing details of the benefits experienced by the interventions described.*
- *Discussing precautions and safety issues which must be considered when using dietary interventions and supplements.*

This presentation will provide information about the processes required when individuals research and implement alternative interventions. It will be of interest to families, carers and individuals with autism who seek to increase their knowledge of dietary interventions and nutritional supplements.

I have only a short time in which to share my experiences with dietary interventions which have helped me to manage some of the more difficult aspects of disordered minerals transport due to low thyroid functioning and mercury toxicity from amalgam fillings.

These dietary interventions include selective food intake, the use of plant based digestive enzymes, minimising fluorine intake and taking vitamin and mineral supplements. I must stress that supplements are not a cure for autism. However, with intelligent observation and experimenting with correct dosage, the careful use of supplements will greatly improve functioning. Autism is a positive adaptation to neurological difficulty so attempts to cure are inappropriate. Supplements can enable an autistic person to attain the best function from limited resources.

In order to improve functioning, malabsorption issues should be addressed in early childhood

when interventions are most likely to be effective. Therapies are of secondary importance to intervention with supplements because they address the symptoms of gut imbalances, not the cause. Additionally, medications have cumulative long term side effects such as liver damage or nervous system damage eg tardive dyskinesia. It is essential to address these issues before adolescence because puberty is a time of regression. The young person needs optimum health to cope with the results of this. Supplements are therefore, really the only long term option.

In my case, all my life, I have had health problems and have never been able to find answers. As a child, until I developed asthma at 4, I was never ill. I did have a pronounced intolerance to milk but that was the only clue that something unusual was happening. As I got older, it was realized that I had no notion of having enough to eat. So as far as I can remember, I have felt hungry, no matter how much I ate. It is now known that gut malabsorption means that some people are starved of nutrients, no matter how much they eat. I am going to describe how all this has changed through the addition of food supplements in my diet.

After being diagnosed as having Asperger's Syndrome in early 2000, I set out to learn about autism. I was strongly influenced to believe that autism was only a neurological disorder, and that the only help was via cognitive behaviour therapy. Often on my travels on the net, I came across small groups of parents who were considered the "lunatic" fringe. These people believed that autism was also a biochemical disorder, and were learning about how the digestive system functions in order to help their children. Over 2 years, the numbers of parents reporting beneficial results from using dietary modification and food supplements appeared to be growing. I also noticed that professional interest in these methods was growing too. At the same time, the knowledge that young children have undeveloped immune systems, and are vulnerable to very early vaccination,

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immune system assault from too many vaccines at once or badly designed vaccines.

At the same time, I found that the mercury preservative, thimerosal, in vaccines has been recognised to be unsuitable for young children. I began to recognise the links between vaccine damage, auto immune disease, gut malabsorption and autism. This was reinforced by the observing that my grandson was markedly effected by the MMR, polio and Hep B vaccines being given same day.

At the same time Andrew, a spectrum adult who lives in Tasmania, became a mentor for me regarding biochemical therapies. He had been researching these for some time, and had considerable knowledge of the issues I have mentioned. He encouraged me to read and post on the yahoo web group, enzymes and autism in order to learn more about the relationship between heavy metal toxicity, autism, auto immune disorders and gastrointestinal disorders.

The first issue we tackled was related to an auto immune metals transport and mineral deficiency disorder. Many autistic people develop auto immune diseases as they age. Many of us have combinations of diseases including lupus, diabetes, Reynaud's Syndrome, Multiple Sclerosis, Crohn's Disease etc. Andrew had discovered that there was an avalanche of evidence regarding the way that fluoride suppresses enzymes. I had been taking Thyroxine for some years, with very little benefit and was also shocked to learn that if a small child eats a tube of toothpaste, death can result.

The first dietary modification I made was to begin to drink bottled water as often as possible rather than rely on the fluoridated water supply. This did help, and almost immediately I stopped needing to sleep after I got home from work.

The next issue we looked at was to do with food allergies. I had always known that I had a problem with milk. If I had even a small amount of cream, or about half a cup of milk, within an hour I would have terrible stomach cramps and diarrhoea. As a child, I self regulated milk and cream, insisting that they were disgusting. Interestingly, it is very common for autistic children to do this while a few favour dairy products almost exclusively in their diet.

At the same time, we were concerned that I might have a gluten intolerance. This can manifest as either a refusal to touch bread or a distinct desire for wheat based products. In my case, I ate a large amount of bread. When I eat wheat products I feel sleepy. I have extreme difficulty with cognitive processing and my reflexes are noticeably delayed. At university, I unknowingly compensated for this by doing 2 hours work every morning before I got up. There was no point after my evening meal as I was unable to comprehend anything that I read.

People who have "leaky gut" also suffer from chronic intestinal yeast infections. These can include Candida, Thrush and Tinea. Medications often suppress the infection for a time, but it always resurfaces. It is important to address the relationship between "leaky gut" and intestinal yeast which results in chronic ill health. In my experience, yeast can usually be kept at bay by using oregano oil, probiotics and plant enzymes.

Andrew suggested that I try Houstonni plant enzymes to help digest any traces of gluten and casein in my diet. I felt some benefit from these and noted that I was digesting food better. However I still had trouble with cognitive processing in the evenings. This was really affecting my family life as I was needing to spend long hours stimming in order to function at work the next day. I decided to try the gluten free/casein free/soy free diet. The effect was electrifying. For 4 days, I felt terrible. I was not eating sugars, yeast or wheat so I experienced yeast die off. This is just like an addict coming off drugs and was most unpleasant. I was quite ill, with headaches, severe mood swings, heightened sensory awareness and a need to stim almost constantly. I was craving sugars and was biting my fingers in order to resist. Parents find this a very difficult time with their children and some cease the diet at this stage because it is so hard to see the child suffering. On the 5th day, I felt totally different. I had energy and dashed out for an early morning walk. I was able to cope with the demands of my job and started to extend my interest in promoting an understanding of autism.

One problem that we did encounter was that the gf/cf/sf diet is not balanced. In addition,

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Tasmanian soils are short of some essential trace elements eg selenium and iodine. This meant that we had to look at food supplements. Using food supplements effectively is not easy. I am concerned that people do not get started on this without understanding the pitfalls. Often large doses of vitamins and minerals are promoted as being necessary dietary supplements. In my experience, this can cause additional and sometimes serious problems. Trace doses are more beneficial, and these need to be tailored to the individual. Commercial supplements often used for children and adults are not appropriate. They are composite formulae which do not take into account the vitamins and minerals that the person is already ingesting, so overdosing can occur. This effect is magnified in people who have restricted diets.

Many people will find that they or their children also need to address other issues like food colourings, additives, or phenol issues. Devin Houston worked with parents to produce an enzyme product called No-phenol which assists the body in coping with these substances. Once again, many people find that the enzymes are sufficient in addressing the problem, while other people find that they do still need to eliminate those substances for a time.

Unfortunately many of the products required are not available in Australia as it does not have the population to support sophisticated supplements. The majority of vitamins and minerals sold here are composites, which mean that individuals cannot control personal requirements. The people I know who are using supplements and enzymes order on the Internet. Andrew and I have found that this is safe if you stick to large, reputable companies. Delivery is usually within 5 working days. I have had several packages checked by customs, and all have been passed. It is ok to order dietary supplements for personal use. I do suggest that people order several products at a time, or freight costs become prohibitive.

Cost is of course, an issue. Because most supplements require small doses, capsules need to be pulled apart and pills cut up. This means that the products last considerably longer than intended by the manufactures. The products are therefore really quite economical although the initial outlay might be large.

All of this is very complex. Andrew strongly suggests that supplement therapy can only be done safely and effectively with Internet message boards. I found that these online support groups where people can pool their knowledge and experiences is an essential part of the process. The enzymes and autism list has Australian members who do help each other with information specific to this region.

In summing up, I am standing here talking to you because of the benefits of dietary interventions. They are not a cure, and as an adult, have limited benefits for me. With careful use, they do permit me to live a busy and productive life rather than to merely survive. I am no longer a slave to an insatiable appetite. I do not experience clinical depression, I work full time, recently managing a stint as a part of my workplace management team. This was a testimony to the improved cognitive functioning I have experienced because the job entailed constant change, a high level of interaction with people and new experiences every day. 2 years ago, this would not have been possible. In the evenings, I rarely collapse with exhaustion or sit stimming for hours in order to be stable the next day. I spend my evenings working on the Autism Tasmania web page, doing other tasks for this organisation, working as a very active member of the A4 steering committee and running an online support group called AutRelate in conjunction with Tony Attwood and Isabelle Henault. All this is due to the support and information from Andrew and the members of enzymes and autism, whose knowledge and experience is available to me 24/7 from my home, via the Internet. In summing up, supplement therapy is most beneficial in early childhood. The Internet message boards and email lists are an essential source of support and information. The most important thing is to understand is that unless fluoride and inappropriate vaccination schedules are addressed, dietary interventions are limited in their effect and that early attention to these issues can address the most difficult aspects of autism.

Geraldine Robinson

Asperger's Syndrome – A personal viewpoint

At the Inaugural Autism Tasmania State Conference, two young men who have Aspergers Syndrome were invited to share their viewpoint in front of a small audience.

Their presentations were amongst those most highly rated by the conference delegates; so in order to bring their stories to a wider audience we are reprinting both their stories in this edition of Autism News. Ed

For as long as I can remember I have had a desire for solitude. It's something that's grown stronger as I've grown older, perhaps because it has become easier for me to find ways to amuse myself by myself the older I've gotten. I think, too, that the unselfconsciousness most children have made it easier for me to socialise. I know from photos of my fifth or sixth birthday that as a child I knew more than a dozen people that I wanted to invite. Today, being friendly with that many people strikes me as impossible. By the time I started attending high school there weren't more than a few people my own age that I spoke to, purely of my own volition, on a regular basis. My strongest friendships, with the only people I can properly call friends, have always been based on mutual idiosyncrasies. It has mostly been the case that the people I have genuine friendships with were to some degree outsiders like myself. Through grade school my best friend was a moderately popular person, but he was also a geography nerd. A strange trait for a twelve year old to have, but it set him apart from other people and this contributed to my liking him, because it meant being friends with him didn't necessarily mean I had to associate with anyone else. Since then the one person I've had a sustained friendship with is something of a nerd, like myself, and moreover he has Tourette's syndrome. This sets him apart from other people in a similar way to how my Asperger's has, which was one of the foundations of our friendship.

In fact, there's a general trend in what socialising I do do that it occurs under specific conditions, although it's not obvious on the surface. Like a lot of people with an Autistic Spectrum Disorder most of my relationships with my peers are based on a common interest and it is that which provides not only the foundation but most of the material for what interaction I have with them. Moreover, through a combination of events, I've wound up having hobbies and interests that are in

something of a minority - such as a strong interest in science fiction and fantasy literature, so when I'm with other people who share then I'm aware that I'm with people who are, perhaps, just a little bit outside the mainstream. I think I find this comforting on some level.

When I was young I could get away with fairly simplistic forms of escape. As a child I was a great builder of cubbies. I constructed from as many blankets as I could lay my hands on and structured them specifically to be warm, dark and cosy almost to the point of claustrophobia. This was a more physical kind of isolation, where I created an enclosed environment separate from everything else. In retrospect I realise that some of my more intensely constructed cubbies were essentially crude sensory deprivation chambers. They were certainly built with a similar purpose in mind. As I got older I subconsciously looked for - and found - more sophisticated ways to distance myself from other people. But even now I prefer dark over light and cosy over spacious.

I found early on that certain activities were a good way to isolate myself. I became an inveterate reader, partially because books are largely a personal pursuit. Not only is reading is something that you do by yourself, entirely separate from anyone else, but since the point of reading is often to move from this world into the one created by the book, I've found reading an effective tool for isolating or separating myself from the rest of the world on several levels simultaneously. Books can be a barrier between yourself and other people while simultaneously occupying your mind so that you don't feel lonely. I've been doing this for so long that by now I honestly feel that books are often better company than people - it has become a kind of positive feedback loop. I have trouble dealing with people, so I isolate myself. By necessity, I become accustomed to this isolation and even learn to prefer it, which in turn makes it harder for me to function in social situations. This cycle seems to have stabilised in the last few years, as I've grown old enough to be consciously aware of when and how my Asperger's Syndrome is a factor in my behaviour, though I don't always go against it.

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It is a rare occasion when I am able to attend a social event of any kind without a conscious effort of will. It may not show on the surface, but inside I have to fight my own reticence and an instinctive sense of not belonging. It's easier if I have a pretext to be somewhere - something that may not mean anything to most people but makes me feel more justified in being in a given place. At something like a university tute or a family gathering I have a sense of my presence being condoned by something external to myself, which makes me more comfortable attending. That doesn't necessarily mean I'm happy to be attending or that I'll participate, only that I can go without a huge build-up of tension.

This is why school and university have been so much easier for me, in some ways, than other parts of my life. They're *ordained*, for want of a better word. The best I can explain it is that the intermittent but recurring sense I have of just not belonging when I'm in the outside world is laid to rest by the fact that I have to be there. My social environment didn't give me a choice in the matter so if I didn't fit in it wasn't my fault. Not that school was all good.

Speaking to you all like this isn't easy, obviously, though I suspect the tension I feel is no worse than a bad case of stage fright that anyone could have. But I have a little advantage in a situation like this. With a few exceptions, you are all strangers to me. In all likelihood I will never see any of you again after this evening. Consequently, it's safe to reveal a little of myself to you because I'll never be in a position where knowing that you know something about me will make me uncomfortable - your anonymity to me makes you less threatening, though on the other hand I can sometimes get paranoid among large groups of people, even if I'm just walking down a city street. That's pretty rare now, however.

Generally, I have more reason to be uncomfortable around the people I see on a regular basis. Friends don't fall into this category because whether or not I see them is something I can determine. Family and, before I started attending university, my peers and teachers at school, are another matter entirely. Before I began attending university school was a particular problem for me. Schools are a unique environment in that they're large enough that you

can find yourself in some pretty big groups of people but small enough that most people know each other by sight and news travels quickly. This combination of factors works to minimise privacy and personal space, which means that under the wrong circumstances they can be a particular kind of hell for someone like me. I won't go into details except to say that the unhappiest times of my life were a result of social pressures at school. The library was often the only place where any kind of peace can be found. University, which is so large that one individual can remain completely anonymous with ease, has greatly reduced this particular source of tension.

The older I get, the easier my Asperger's is to deal with. Not because its effect lessens - and there are still times when it dictates my behaviour, and I know that it is and still can't do anything about it - but because I gain experience in either conquering it or working with it. As I begin to wield more control over my own life it becomes possible to structure it in a way that works for me. Just a little bit of independence is something I find very therapeutic. Right now, I can honestly say I'm as content with my life as I've ever been.

Ben Gardner

ANNUAL GENERAL MEETING 2003

Sunday 17th August at St. Giles,
Amy Rd, Newstead,
Launceston

- 10.30am - Morning tea
- 11am - Annual General Meeting
- 11.30am - Forum (with Facilitator)
- 1pm - Lunch

RSVP Penny Cromarty

Ph 6334 1119 by

Thursday 15th August

Living with an ASD

My name is Alex Hodge. I am nearly 18. I have two brothers, Thomas is 15 and Isaac is 12.

I found out that I have a Pervasive Developmental Disorder, when I was in grade 5. I was 10 years when I saw a specialist in Hobart. Before this I had speech therapy, occupational therapy and physiotherapy. I went to an early intervention language unit when I was three and a half years old. I went to East Launceston Primary School and Queechy High School in Launceston.

This is the first time I have been to a conference or anything like that. I have mild Tourette's and occasionally have tics. I don't know much about it though. I can control my tics when I am out, whereas at home sometimes they are noticeable. They come and go and they change. Sometimes I have a verbal tic or grunt and sometimes other minor tics come and go. I don't like talking about it much.

Mum has always talked to me about Autism. I think my family has been good and they have helped me to find out the person I am and that I am just a normal person.

I know that there are some things I find difficult that others find easy. Sometimes I find it difficult to read how other people are feeling, I can tell when people are angry or happy, but the less obvious feelings are harder for me to notice, for example feelings and emotions that are mixed in the mind. It is obvious on the face, I can tell how people feel. I find it hard to know what people are thinking.

I like being friendly to people and don't like being cruel, and therefore it makes it hard for me to say No, for example I often find it hard when 2 or 3 mates phone up to see what I'm doing and I'm left with plans for each friend. It leaves me confused over what I should do. I am now starting to learn that sometimes I have to say No and make plans with one friend at a time.

I sometimes get annoyed when I can't make my own decisions for myself, however I realise that sometimes I need people (friends, family, etc)

to help me make decisions that will help me, both short-term and long-term. I am starting to make my own decisions, however I find it hard thinking things through and deciding what is best. I used to try to fit in with others, but I now realise that it's a load of crap. I figured out that I can have friends being who I am and just being myself.

I go to Newstead College and am in year 12. There are parts of college that I am not enjoying as much this year. I am struggling with some subjects, I know that I can't comprehend certain parts of subjects and also know that other students can. Sometimes I find it hard to concentrate in class when teachers give lots of information at once. I try to write everything down but sometimes I only get about a third written, because teachers talk and write so fast and it makes me angry and up-tight.

At high school I got good marks and school seemed easier. The hardest thing at college is that teachers don't seem to help as much and they expect more. I don't like asking for help, but I am learning to and it helps me. I'm not very good at organising my time, I tend to get disorganised and stressed. When I get stressed I can't think and I go off into a fog. I get frustrated when lots of instructions are said together because I know that I have to finish one task before moving on to something else. Sometimes I think things through aloud and it helps me work things out. I only talk out loud when I am by myself.

I am currently seeing a student counsellor at school. Mum introduced me to him last year, but now I arrange to see him by myself when I need help. He is helping me organise and think about what I am going to do next year.

There are lots of good things about college. I have made lots of friends, from both sexes. Andrew is my longest friend, I met him in grade 5, he has albinism and I have helped him at school and he helps me.

I don't really mind that I have a disability. I don't tend to think about it much and I am who I am. I can't change things or the way I am and I'm happy most of the time.

Alex Hodge

What I would do if I were a Parent of an Autistic Child: *Recommendations Based on 25 Years of Research Experience* Written by Stephen M. Edelson, Ph.D. Center for the Study of Autism, Salem, Oregon

This article has been reprinted from the www.autism.org site. Although some of the information is specific to North American readers, it still contains much of interest to Australian readers

Over the past 25 years I have been fortunate to conduct research in several areas of autism and to collaborate with many of the leading pioneers, including biomedical (Bernard Rimland), behavior/education (Ivar Lovaas), and sensory (Temple Grandin, Guy Berard, Lorna Jean King, Melvin Kaplan, Helen Irlen). These experiences have helped me broaden my understanding of what can be done to help these individuals.

One of the most difficult and stressful times for a family is when they first learn that their child has autism. Parents are then faced with a critical and life-determining question: What should I do to help my child? The decision on which treatments to implement (and not to implement) will likely determine the child's prognosis. I have outlined the steps that I would take if I were a parent of an autistic child.

Action Plan First, I would write to the Autism Research Institute (ARI, 4182 Adams Ave., San Diego, CA 92116; fax: 619-563-6840) and request their free parent packet. Much of this information is on their website: www.AutismResearchInstitute.com. The packet contains a wealth of information that describes ways to understand and to treat many problems associated with autism. It includes a sample issue of the quarterly ARI newsletter, the *Autism Research Review International (ARRI)*. Subscribing to the ARRI is the best way to keep informed (US\$18/year).

I would also contact the local chapter of the Autism Society of America (ASA) in my area. The autism chapter will likely provide valuable resources and contact numbers in the community and throughout the state. In addition, I would attend at least one parent support group to see what they have to offer. ASA maintains a listing

of most autism chapters throughout the country (toll-free: 800-3-AUTISM).

Important note: Before contacting my health insurance carrier, I would first read the policy. Many policies do not cover treatment services for autistic individuals. These insurance companies may reimburse therapies if the therapy is not specifically aimed at treating autism and if the insurance company is not aware that the child has autism. For example, if the child has a speech problem, the insurance company may pay for speech therapy.

Intervention There are two major approaches that I would pursue simultaneously; and the earlier these interventions are started, the better the child's prognosis.

The first approach involves determining whether the child has health problems. These problems may include a critical need for essential vitamins and minerals (e.g., vitamin B6 with magnesium, DMG, vitamins A and C), gastrointestinal problems (e.g., leaky gut, yeast overgrowth, viral infection), high levels of heavy metals and other toxins (e.g., mercury, lead), food sensitivities and allergies, and more. The majority of autistic individuals have one or more of these problems.

The Defeat Autism Now! (DAN!) approach to autism addresses these biomedical issues. ARI distributes a diagnostic and treatment protocol titled *Biomedical Assessment Options for Children with Autism and Related Problems*. A list of practitioners who understand and know how to treat such medical conditions can be obtained by writing to ARI or visiting their website www.AutismResearchInstitute.com. Of the many treatments described in the protocol, I would first give the child vitamin B6 with magnesium, then dimethylglycine (DMG), and then the gluten-/casein-free diet.

Comment on drugs. Some paediatricians prescribe drugs to autistic children even though the Food and Drug Administration has not

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approved any drugs for treating autism. Additionally, almost every drug has harmful side effects. I sometimes hear reports of some benefit with Risperidal, Prozac, and Ritalin. However, it is very likely that even greater improvements will occur following other, non-drug, biomedical treatments (see ARI's publication: 34Q).

If the child talks very little or not at all, I would have the child tested to see if he/she has seizures. Seizure activity may affect speech production. An electroencephalogram (EEG) measures brain wave activity, and it may be able to detect seizure activity. If the child does have seizures, I would use non-toxic nutritional supplements to treat the seizures, such as vitamin B6 and DMG.

The second approach is behaviour/education. Applied behaviour analysis (ABA) is a well-documented and effective teaching method for many autistic children. This method involves 1-on-1 instructional sessions and utilises educational tasks that have been developed specifically for autism. *Teaching Individuals with Developmental Delays: Basic Intervention Techniques*, written by O. Ivar Lovaas, is an excellent resource and describes, in detail, how to implement this method.

After the biomedical and behaviour/education interventions are well underway, I would direct my attention to the child's sensory problems. Many autistic individuals suffer from a **hypersensitive** or **hyposensitive** sensory system. These problems may involve:

- hearing (e.g., sound sensitivity, appears to be deaf),
- vision (e.g., light sensitivity, visual attention problems),
- tactile (e.g., sensitivity to touch, insensitivity to pain),
- vestibular (e.g., craves or resists certain movements, such as swinging),
- proprioceptive (e.g., excessive jumping),
- smell (e.g., sensitivity or insensitivity to odors), and
- taste (e.g., picky eater, pica behavior).

There are several interventions that can reduce or eliminate many of these problems, such as Auditory Integration Training (hearing), vision training and the Irlen lenses (vision), and sensory integration (vestibular/tactile/proprioceptive).

The three treatment approaches outlined above complement one another. Autistic individuals often become more attentive and more motivated to learn soon after treating their biomedical and sensory problems. A child may do well with only one these approaches, but the combination can lead to amazing results, and even recovery for some children.

The next step. It is also worth looking into other effective interventions for autism, such as structured teaching, social stories, the Greenspan method, Picture Exchange Communication System (PECS), and Grodin's relaxation/visual imagery techniques.

Family issues. Raising an autistic child can be very stressful to the entire family. Siblings sometime feel ignored because so much of the parents' attention is directed toward the autistic child. Divorce is quite common among families with an autistic child. Additionally, relatives and close friends may distance themselves. It is important to be aware of these dangers and address them if they should occur.

Finally, it is important to be a strong advocate for the child. Many professionals are aware of the symptoms associated with autism. However, they do not know how to treat them. Information is a powerful tool. I would keep all of the child's documents and diagnostic test results in one well-organised folder. Whenever possible, I would provide relevant articles and other informational materials to therapists and other professionals who work with the child. Like many other parents of autistic children, I would likely wind up teaching professionals how to work with the child.

It is important to realise that autism is treatable, and there are many resources available, such as books, newsletters, Internet websites, and conferences. I would start with the following resources:

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Books

General Resources

Autism Research Review International newsletter (quarterly). San Diego: Autism Research Institute

Gerlach, E.K. (2000). *Autism Treatment Guide*. Second Edition. Arlington, TX: Future Horizons.

Hamilton, L.M. (2000). *Facing Autism*. Colorado Springs, CO: Waterbrook Press.

Biomedical Approach

McCandless, J. (2002). *Children with Starving Brains: A Medical Treatment Guide for Autism Spectrum Disorder*. Paterson, NJ: Bramble Books.

Pangborn, J.P., & Baker, S. (2002). *Biomedical Assessment Options for Children with Autism and Related Problems*. San Diego: Autism Research Institute.

Seroussi, K. (2000). *Unraveling the Mystery of Autism and Pervasive Developmental Disorder*. New York: Simon & Schuster.

Behavior/Education

Leaf, R., & McEachin, R. (1999). *A Work in Progress: Behavior Management Strategies and a Curriculum for Intensive Behavioral Treatment of Autism*. New York: DRL Books.

Lovaas, O.I. (2002). *Teaching Individuals with Developmental Delays: Basic Intervention Techniques*. Austin, TX: Pro Ed.

Conferences

General Resources - Autism Society of America - www.autism-society.org

Biomedical Approach - Defeat Autism Now! (DANI) - AutismResearchInstitute.com

Behavior/Education - Families for Early Autism Treatment - www.feat.org

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Brunei Story

In February I was doing the routine task of checking my e-mails. As usual, there was a lot of 'junk'. I scrolled down the list, deleting as I went, until I reached one headed: **Autism Conference in Brunei**. I only opened it because it began – Dear Rose..... This email was, in fact, an invitation for me to speak at the 2nd National Brunei Autism Conference, in March this year! Not only was I surprised by this invitation from out of the blue, but when I glanced at the television on my way to get the atlas to look up Brunei's location, "Getaway" was on and the presenter was talking about Brunei at that exact moment! Brunei, I subsequently found, is on the island of Borneo and is predominantly a Muslim country. The climate is similar to Singapore's and is about 32 degrees every day. (Brunei was a British Protectorate until 1984 and still has strong ties to the UK.) Although Malay is the language spoken widely, all children are educated in English from Grade 4 onwards.

The invitation to speak came from Debbie Smith, whom I'd met some years before, when she worked at the University of Tasmania. Debbie is now a lecturer in Special Education at the University Brunei, Darussalam and she is an integral part of the autism community in Brunei. Apparently, her reasoning behind the invitation was that Tasmania and Brunei are roughly the same size and have quite small populations – Brunei's is in fact smaller than Tasmania's.

A dedicated group of parents in Brunei were committed to raising awareness of Autism in Brunei and, at the time of my invitation, had only been in operation for 18 months. Debbie had made them aware of Autism Tasmania and they were interested in how we provided information, support and services for those with ASD. The name of the Brunei parent organisation is **SMARTER**, which is an acronym for: **Society for the Management of Autism Related issues, in Training, Education and Resources**. Shortly after SMARTER Brunei was formed this dynamic group presented the Inaugural Brunei Autism Conference in 2002, inviting Dr Verity Bottroff from Adelaide to be their keynote speaker.

After giving the invitation some thought, I did accept and subsequently learned that I was to give three papers (which became four with the summary of the conference at the close of the third day). The titles of the papers were: Autism Tasmania and it's Beginnings, My involvement with Autism Tasmania and Our Personal Journey with ASD. Although it is a young organisation,

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SMARTER Brunei had the support of Rotary International, which offered to sponsor a speaker from Malaysia; and the Australian High Commission, which offered to sponsor a speaker from Australia.

I arrived in Brunei (after a very long day) on March 23rd into 32 degrees and bright sunshine. The chairman of SMARTER Brunei, Malai Hj Abdullah (Malai for short) and Debbie Smith met me and looked after me wonderfully for the next 5 days.

During that first day in Brunei I visited their brand new, not yet open Autism Centre, which will be extremely well equipped to offer an Early Intervention Program to the children of the members of SMARTER Brunei (Remember this organisation had only been in existence for 18 months!).

The Centre commenced operations on March 28th, the day after the conference ended. It is open for 7 days a week from 8am until 10pm for families. The major focus is on the S.T.E.P. Development Program. (Social, Training, Education and Psychology). The Centre uses the following education systems: Visual Strategies, Sensory Integration, PECS System, TEACCH System and the LEAP program. There are conditions of acceptance into the centre – some of these include:

- parents must be members of SMARTER Brunei,
- children must not be following any other program - apart from main stream school programs or other programs which are accredited by the organisation,
- parents must be willing to attend the Centre everyday for the "one on one" program at least 20 hours per month
- fees are \$100 (Brunei) per month for each child.

The conference itself was very well organised, with the theme: "The Autistic Individual is not Disabled, Just Different." As it ran over three days, there were varying numbers of people attending each day, with an average of about 80, which was very impressive. There was also a

good cross-section of parents, paediatricians, clinic sisters and teachers attending each day.

The delegates were very interested in Tasmania and Autism Tasmania; how we started and what we have achieved in our 10-year history. They were particularly interested in the appointment of a Family Support Co-ordinator and the type of support families can receive.

Parents were especially interested in my own family's personal journey with Thomas through the education maze and, in particular, our involvement with the establishment of Giant Steps. In break times – especially at morning tea, where the local delicacies of curry, dried fish and rice dishes were served, there were many questions regarding the autism connection and also about Tasmania itself! One mother was amazed I was going to see some of the local monkeys at the end of the day's proceedings (they roam around in the trees everywhere) and she was astounded that Tasmania did not have any monkeys! It was also difficult to describe our climate, especially the colder weather, such as frosts and ice on the roads.

The speaker from Malaysia, Mr Wong Chee Kim gave a wonderful presentation about the school the parents have established for children with Autism Spectrum Disorder, called the CAC Sunshine Centre. It incorporates a multi-faceted approach including Sensory Integration and PECS. The photos showed exactly what a vibrant centre it is and well worth a visit in the future!

There were many wonderful papers; including a parent's perspective of the World Autism Congress in Melbourne, which a team of SMARTER Brunei attended. For me the most remarkable piece came from the President of SMARTER's daughter, Suryani, who wrote a poem about her brother. It really emphasised to me the awareness and feelings of a sibling. It is called "Little Brother." (The poem is on the last page of the newsletter.)

I thoroughly enjoyed my 5 days in Brunei, it highlighted that, no matter where we are in the world, we share a need for information, support, and expertise from professionals plus appropriate service provision. As Malai said at the end of the conference: "Your actions reflect your intentions."

Rose Clark

JANUARY 2003 - California Autism Epidemic Increasing

According to the latest figures just released by the California Department of Developmental Services, in 2002 California experienced an astounding 31% one year increase in the number of new children professionally diagnosed with the most severe cases of autism entering it's developmental services system. The 31% one year increase from 2001 to 2002 represents an all time record number of new cases in the system's 33 year history.... 3,577 new severely autistic children added in just the past 12 months.

The figures reported by the Department DO NOT include persons with PDD, NOS, Asperger's, or any other autism spectrum disorders, just those who have received a professional diagnosis of level one, DSM IV autism.

According to the Department, eight years ago, in 1994, there were 5,108 cases of level one autism in the entire system, as of January 6, 2003, there are now 20,377 cases of level one autism in the system.

From 1971 to 1980, California consistently added one to two hundred new cases a YEAR. In 2002, California added 3,577 new cases. Since 1980, the documented start of California's autism epidemic, the numbers of new cases have exploded to where we are today with California adding, on average, 10 new children a day, 7 days a week with the most severe form of autism to it's system, an increase of over 2 additional new children per day over the 2001 rate of 8 children a day. Keep in mind that from January 1994 to January 1995, California added on average 2 new children a day.....today we are adding 10 children a day.

One only needs to examine the age distribution of the persons in the system to recognise the genesis of this epidemic. Over 81.5% (8 out of 10) of the autism population in the system were born AFTER 1980.... with 2

out of 3 persons in the system currently between the ages of 3 and 13 years old, compared to 18.5% (less then 2 out of 10) who were born BEFORE 1980.

Autism now accounts for 40% of all of the new intakes to the system, making level one autism the number one disability entering California's DD system. (The other eligible conditions besides level one autism are mental retardation, cerebral palsy, epilepsy, and other conditions similar to MR.) As a result of the fact that the inclusion of new cases in the data system begins with children 3 years of age and older (ages 0-2 are not collected on the CDER database), and since mercury containing vaccines are still in use today, including the most recent recommended addition to the childhood immunisation schedule ... two shots of flu vaccine for babies (bringing the total number of doses of vaccines to 41 for a baby in California before the age of 2 years old), therefore it will take a few years to start seeing the effect of the phasing out of the mercury containing preservative Thimerisol from childhood vaccines on the autism epidemic.

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Leisure Activities for Adolescents with Autism

This article was presented at the Autism Tasmania State Conference in Hobart 2003. Marian Quinn is employed at Giant Steps Tasmania as a Teacher and currently runs the Adolescent Group operating out of Launceston once a week

Leisure is one of those fluid concepts that we all understand but find difficult to define. Perhaps the central issues are choice, enjoyment and a sense of achievement or purpose. Leisure might therefore be defined as:

Engagement by choice in an enjoyable activity that provides a sense of achievement and meaning.

Among the general adolescent population leisure has been reported as accounting for 50-57% of most young people's time. For the majority this decreases as they are forced to take on paid work, but many individuals with autism continue to have a large amount of leisure time. This presents peculiar difficulties since the structured and predictable nature of work is often a more comfortable environment for autistic adolescents than the less consistent nature of recreation. Leisure, therefore, is as potentially stressful and challenging as it can be rewarding and enjoyable.

Despite these challenges leisure is an important aspect of every young person's life; it alleviates boredom and provides opportunities for physical fitness, socialisation and building self confidence. Boredom can be a problem for both neuro-typical and autistic adolescents. Psychological theories suggest that boredom among adolescents is caused by: a lack of awareness of stimulating things to do, a lack of intrinsic motivation to act (for those with autism this may include an inability to recognise and label boredom), or a mismatch between personal skills and the challenge at hand (Caldwell et al, 1999). We need to assist our adolescents to develop a range of enjoyable activities in which they can experience success, and to make independent choices among these activities. A young person who chooses to engage in physical activity is able to reduce his anxiety, sleep better, improve his overall fitness and prevent weight gain.

As well as contributing towards physical wellbeing leisure activities may have a positive effect on mental wellbeing. A study by Passmore (2003) found a strong positive correlation between some leisure activities and mental health in adolescents. The activities found to be most effective in this regard were those involving the mastery of new skills and achievements; these in turn led to an increase in both self-confidence and self-efficacy. Time-out leisure (e.g. reading a book, twirling, having a coffee, rewinding a video, etc) on the other hand, did not improve mental health.

Leisure can also play an important role in providing opportunities for socialisation. Adolescents with autism may find it difficult to initiate interactions, by participating in activities with other students they develop their awareness of others and create a framework for casual conversation. (This does not mean that casual conversation will automatically occur, this may also need to be specifically taught.)

When choosing a leisure activity the individual's interests and abilities should be taken into account. This is meant as a guideline, however, rather than a restriction. While leisure activities should eventually be fun, many individuals with autism initially resist anything new or unfamiliar. In order to extend their choices it may be necessary to persist in a non-preferred activity long enough for it to become familiar and for the individual to experience success. While there are a number of disability specific organisations offering leisure programmes or support it is also worth contacting different organisations in your community and see what they have to offer. Try service, neighbourhood, recreational, church, and specific interest groups. It is also important to choose activities that fit in with your family and lifestyle (what would you like to do with/support your child in? what do you have time for?), otherwise they are unlikely to be done regularly.

Once you have chosen an activity it can be very helpful to clarify your goals. You may find that you have a number of different expectations for

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ACA Reform Continues.

The reform of the Autism Council of Australia (ACA) continues, with the new constitution adopted, most directors of the restructured Board appointed and the first AGM under the new structure scheduled for mid-October 2003. The objective of these changes is to make the ACA a more open and relevant organization to the wider autism community and to give it a formal structure that enables it to be recognized at a national level by the Commonwealth government. ACA will then be able to legitimately speak on behalf of the autism community, have formal involvement in the national disability forums that are currently without an autism voice and help shape the priorities and activities in autism research.

Membership of the ACA is now open to any person, group or organisation with an interest in the autism field - it is no longer the sole preserve of the state autism associations. Each year, a Forum will be held, involving 2 representatives from each state's autism association plus 10 people elected from the wider membership - the Forum provides advice on policy, discusses national initiatives and generally exchanges information and helps shape the direction of the ACA. It also elects the Board, which comprises 1 person from each state autism association, 3 elected from the wider membership attending the Forum and the Chairman of the ACA Professional Committee (currently Dr Verity Bottruff).

The eight current directors are mainly presidents or CEOs of state autism associations - the President is Andrew Brien (from ACT); Vice-President, Joan McKenna Kerr (WA); Secretary, Adrian Ford (NSW); and Treasurer, Chris Renshaw (SA). Mick Clark is Autism Tasmania's nominated director. The three directors from the wider membership will be elected at the first AGM/Forum in October. Discussions are well underway with Northern Territory groups to bring one of them onto the ACA.

The Board will meet six times each year - two

will be face-to-face, the others by teleconference. The plan is to have an ACA Board meeting in Adelaide on Friday, 24 October, 2003 and the AGM and Forum on Saturday, 25 October. The Board can meet again on Sunday, 26 October to conclude business if required.

As many people are aware, a grassroots autism advocacy group called A4 (Autism & Aspergers Advocacy Australia) has been formed, driven by a small group led by Bob Buckley from the ACT and Judy Brewer Fischer. ACA President. Andrew Brien is also involved in this steering group. Membership is free, giving everyone in the Australian autism community a means of being involved with what is happening internationally and nationally. By definition, it is a less formal organization and is unable to operate in the sort of forums open to the ACA. Conversely, the ACA cannot have the same flexibility and responsiveness as A4.

Working together is essential! The ACA & A4 are committed to the same principles:- high grassroots involvement from everyone in the autism field, achievement of a national profile and goals, development of effective public policy that meets the needs of people who have autism and their families. People from both groups are seeking ways of working together on priorities rather than duplicating efforts.

The ACA is focused on getting its own house in order - identifying priorities, accessing funding and working to achieve recognition and participation in national forums. One of the first practical decisions on working together has been to focus on a truly national Autism Awareness Week in 2004. Similarly, the ACA website is being revamped to reflect the changes and new direction. The real test will be the extent to which the ACA can bring a national focus to autism matters and build on the energy and activity in other places.

Mick Clark

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the one activity. You would like your child to get fit, have fun, be independent, learn new skills, follow rules, improve his communication skills, socialise with those around him and relax! Although all of these may be valid goals it is unlikely that they can all be achieved at the same time. Decide on what you feel is most important at this time and focus on that.

In order for adolescents with autism to participate meaningfully in leisure activities some preparation may be required. This may involve teaching background skills, communicating with other participants and providing structure. While many skills are learnt during the leisure activity some are best taught in a structured setting beforehand. For example, if the goal is to go out for afternoon tea, then the skill of sitting for a certain length of time may need to be achieved. On other occasions skills may be introduced in a structured setting (where there are fewer distractions, more time, and expectations can be made clearer), then further developed within the activity. Communication can be central in ensuring that all individuals involved are working towards the same goal. Aides, organisational staff or fellow participants will benefit from knowing your goal and how best to interact with your child in order to achieve it.

Another aspect of preparation is the incorporation of structure into the activity. We can help to alleviate some of the stress caused by the unfamiliar or unpredictable nature of leisure by the use of schedules and social stories. Schedules show when the activity will occur and what will happen afterwards. Social stories can forewarn and reassure the individual regarding what might happen during the activity. Within the activity visual cues may increase a person's ability to participate independently.

In each leisure activity the aim is to develop independence to the level of the adolescent's ability. Regular review of the activity in order to determine the next stage is an important part of this process. It is also valuable to involve a range of people in directing the activities. When we work intensively with someone for a long period of time we become very attuned to their strengths and limitations, this can unconsciously restrict our outlook. Someone who is less familiar may present them with unexpected challenges, and they might just surprise us. In the same vein it is

also valuable to make use of one off leisure opportunities as they occur. A new setting may be a catalyst for the emergence of new skills.

In conclusion it is worthwhile noting that, although leisure activities can be challenging, they should also be fun! If we lose sight of this we miss the whole point of leisure.

Marian Quinn

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Dear Little Brother

Dear little brother,
You are but 5 years of
age,
You are so sweet, fair and
innocent,
You have been blessed by
God's grace.

Dear little brother,
You are so special to me,
So loved you are by all of
us,
By your family.

Through all the happiness
and joys,
That your presence brings,
Through all the years you
have lived,
What saddens me brother
is just one thing.

No matter how hard we
try,
No matter how much we
long and yearn,
We cannot show you the
amount of love,
That we so much want to
return.

Some mornings I see you
crying,
Screaming and banging as
strong as you could,
We try everything to make
you stop,
But you remain
misunderstood.

It pains me to stand by
helpless,
With you in the world so
vulnerable,
Whatever the future that
we've dreamt for you,
At most times seems so
doubtful.

It pains me brother,
For I know not what you
need,
I know not what you feel,
or think,
I know not of what it is
you dream.

Could it be that you want
chocolate?
Sweets? Were you bitten
by a bug?
Are you hurting? Sleepy?
Or do you long for a hug?

Still I stand there
helpless,
Only to watch you scream
and cry,
The only thing I can
ponder,
Little brother, is why?

I wish you could
understand what I mean,
When I say I love you,
Or how much I long to
hear you say,
I love you too.

I pray little brother,
That youth shall remain
by my side,
So that maybe one day
brother,
You can *tell* me why you
cry.

*Written by Sh. Suryani Hj
Malai Abdullah.*