



# AUTISM NEWS

Jan 2003  
Volume 1

## From the President

Welcome to the first edition of the new Autism News. This first issue is full of articles written by our members on the recent World Congress and the ECIA conference and should make interesting reading! We intend to produce several issues per year.

In future editions, we intend to include articles that cover a wide interest range and we would appreciate feedback and participation from our members. This may take the form of suggestions of articles for inclusion, personal journeys or stories, and constructive advice as to how we can improve our delivery.

## Impressions of the Congress: Geraldine Robertson

Many of you have heard that the Inaugural World Congress was very good. What many people do not know is that there were actually two conferences. One was high profile. Many experts and professionals from all over the world attended. People with ordinary lives were able to attend as well. They enjoyed mingling and sharing. This pleasure was denied most AC

(autistic cousins) adults because of the nature of autism. Another issue which causes some grief to many autistic adults is that when they go to conferences, it is in a very passive capacity.

A big thankyou to all those who have contributed to this publication and in particular, Cheryl who compiled it

Happy Reading

**Rachel Hodge**

President  
Autism Tasmania

I had an idea which would enable a sharing between experts by circumstance and the acknowledged experts.

*(Continued on page 2)*

## Inside this issue:

From the President <u>Congress</u> Geraldine Robinson	1
<u>Congress</u> Rosemary Rush	3
<u>Congress</u> Julie Hatters	4
<u>Congress</u> Jodi Woodhall	5
<u>Congress</u> Scott Woodhall	6
<u>Congress</u> Ros Ward	7-8
<u>ECIA Conference</u> Lisa Minchin	9
<u>ECIA Conference</u> Anne Wilmshurst	11
<u>Parent line</u> Leisure options/ QANTAS	13
<u>Parent line</u> Shaving	14
A4	15

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*(Continued from page 1)*

Dave Borland, a Congress committee member helped me to bring that information and pleasure in sharing to a group of autistic people from all over the world.

The second conference took place in a quiet corner called The Retreat. We set up a small network of computers loaned by ComputerBank Victoria. Speakers posted their papers online for autistic adults to read. At 8.00 am each morning a speaker gave his/her time to discuss their papers online with people from many countries. Some of these people live very restricted lives, either in supported accommodation or rarely leaving their homes. For many, English is a second language, and some are non-verbal. These people were delighted to have an opportunity to communicate with Donna Williams, Dr Robyn Cosford, Dr Tony Attwood, Dr Isabelle Henault and Dr June Groden.

My goal was that the learning would not be one way and that hope was realised. All the speakers were amazed at the difference between verbal and online conversation. Some were not prepared for the intelligence and eloquence of participants. Nor were they prepared for the strong sense of community experienced in Autism only chatrooms.

Dr Robyn Cosford talked to us about the metabolic profile of people with Autism and Asperger's Syndrome. Her information about diet and supplements was cutting edge and is in line with international research. Dr Cosford generally works with children, so she was interested in the correlation between her research and the experiences of adults. She is considering making her research more accessible online - a boon for a population who do not have the financial resources to purchase texts.

June Groden discussed stress management. She had some good practical suggestions that could be practiced without formal therapy sessions. She was also interested in the potential for online support groups which encourage self help.

The sexuality session led by Tony and Isabelle was fascinating. Autistic people were pleased to see that their impressions of the autistic sexuality profile is being supported by research. It was noted that our concerns are the same as those experienced by people everywhere however the solutions to those concerns may be very different.

A very important issue came up. The questions asked by young people revealed a heart-rending loneliness and isolation. These young people do not have the access to peer support experienced by most adolescents. It is very obvious that we need to consider a means to provide that support and accurate autism specific information online.

One speaker commented that often therapy requires participants to do a large amount of reading. Many people with Asperger Syndrome are hyperlexic, so reading about issues that are challenging for them is a hindrance to therapy, not a help. Another issue was that many people on spectrum also have Central Auditory Processing Disorder (often undiagnosed). This means that oral information is not being processed accurately. Therapy sessions need to take these types of issues into account.

My net friends and I hope that online discussion will become a part of all autism conferences in recognition of those with differences that do not permit face to face participation.

I would also like to thank Eileen Prunster who encouraged me when organisation difficulties seemed insurmountable and Andrew Levin, whose advice on the

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*(Continued from page 2)*

benefits of dietary supplements alleviated my sensory difficulties to the extent that I could participate actively in Melbourne.

**Geraldine Robertson**

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## **Impressions of the Congress: Rosemary Rush**

Delegates to the Congress who spoke about their Autism/Aspergers experience made a considerable contribution to the inclusive nature of the event. A few are represented below.

Max Williams was the “face of the Congress”, young and eager to have others understand ASD. As part of the opening ceremony Max conveyed his enthusiasm for this goal to become a reality.

Donna Williams resonates with the world. Her skill in conveying her sensory experiences kept me transfixed each time I heard her speak. Donna described her life so far as a timeline of eight stages.

1. Born in 1963.
2. Up to age nine (9) – Described her being as an “instrument of resonance”. In experiencing a beaded curtain on a window Donna would become that beaded curtain. She was, in fact, a world to herself.
3. 1972 – Donna noted that at this time she had started vitamins. Donna could put three sentences together receptively. She was able to hear all of the words.
4. Age thirteen (13) – Donna took on lots of things from the television. I do not know if they were actions, language or both. Donna told us she was scared that she was still emotionally three years old. It would be interesting to learn if Donna was speaking with hindsight or if she had that self-awareness at thirteen. Phrases from advertising jingles were used.
5. Age twenty five (25) – At this time Donna became ill with food allergies and intolerances. Getting answers to questions

about self was happening and this was also the phase in her life when Donna wrote her books.

6. Age thirty (30) – There came a simultaneous sense of self.
7. Age thirty eight (38) 2001 – Donna celebrated the beginnings of days away from exposure anxiety with the assistance of medication.
8. Age thirty nine (39) 2002 – The present time of Congress. Donna tells us she is doing OK and is able to connect. Donna had a male partner accompanying her at the Congress.

Wendy Lawson spoke about matters of attention and that thinking ahead can only occur when there is interest involved. It makes sense in that case to teach through one’s interests as interest is a pre-cursor to motivation.

In discussing behaviour support, Wendy spoke of presenting the idea to an individual that a particular behaviour gets in his/her way. For example the student who does not want to be sitting outside the principal’s office can prevent that situation by changing his/her behaviour in a situation to a low level response. He/She can be taught about their low level behaviours.

Dr Ruth Baker from New Zealand spoke of “cousins” in the population who have no professional diagnosis and warned that those without a diagnosis run the risk of a moral “default” label from the community, for example naughty, obnoxious, violent etc.. These people are consequently denied access to specific services and

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resources that would support them and in the worst case scenario, a psychiatric disorder results.

Chris Mason, an artist working out of Arts Project Australia, is achieving success in his paintings and ceramic work. An exhibition was held coinciding with the Congress. His portrayals of the female body show great talent. About Autism Chris says "It's not the end of

the world and it doesn't bother me."

**Rosemary Rush**

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## Impressions of the Congress: Julie Hatters

In Dr A. Ruth Baker's presentation (11.11.02) and paper entitled "The Invisible end of the Spectrum = Shadows, Residues "BAP" and the Female Aspergers Experience", she points out the difficulties and needs of the individuals who often fail to obtain "accurate" recognition of their ASD, usually because they are at the high-functioning end of the spectrum and may not meet full criteria for an ASD diagnosis.

Terms used by professionals to describe those whose symptoms lie in this area of the spectrum may include: residual Aspergers Syndrome, autism shadow syndrome, ghosting of autism, autistic tendencies, mild aspergers, loners or broader autistic phenotype (BAP). There are those whose ASD has never been recognised, those who are misdiagnosed and those whose presenting problem is recognised (such as anxiety and/or depression), but not their underlying ASD. Some individuals may no longer meet full criteria as adults although they did as children, or may meet only 1 or 2 of the components of the triad of impairments, however, they may still be suffering many difficulties due to their existing autistic traits and surely deserve recognition and assistance.

There are those who are considered "too

mild" or show imagination, theory of mind, empathy or humour, plus many women and girls who tend to also present differently – all whom may fall into this "no-mans land" category. Dr. Baker points out these people still require "autism based" explanations and strategies for their difficulties, to replace moral judgements; follow-up support to accompany any diagnosis; the opportunity to know about and access the autistic community, and above all – understanding. Dr Baker also points out the need for those at the lower-functioning end of the spectrum to have their co-existing ASD recognised if they may already have another diagnosis, eg: intellectual disability, since such an individuals needs would be quite different in environmental and interpersonal terms, due to the existence of the ASD.

There are many misconceptions about people at the high-functioning end of the spectrum and their problems may seem invisible to most non-autistic people. Non-Autistic individuals may easily be led to an inaccurate conclusion by noting the capacity of many of their ASD cousins to hold down a job and/or marriage, for instance. However, the often numerous underlying, but "hidden" difficulties involving such areas are easily overlooked by outsiders and any anomalies tend to

*(Continued on page 5)*

(Continued from page 4)

be quickly labelled inappropriately due to others lack of understanding.

Females particularly tend to be under-diagnosed. There is still little literature available regarding female presentation of ASD, but it does suggest that they present differently. Female ASD behaviour tends to be interpreted incorrectly; as the girls grow older and more observant (with increased awareness), they tend to try and modify their apparently "inappropriate" social behaviour. This may take the format of becoming silent, anxiously careful and mimicking others' "more acceptable" behaviour, including an attempt at eye contact. If undiagnosed, they tend to receive moral labels or moral judgements from others eg: rude, obnoxious,

arrogant, stupid, lazy (just try harder), overanxious, weird/strange, selfish and so on. The value of the individual concerned knowing of their own ASD should not be under estimated, even though their symptoms may appear mild. Then, instead of feeling frustrated at being so misunderstood and badly judged (including by themselves), they could have the chance to feel understood, valued and respected – surely everyone should have this right?

**Julie Hatters**

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## Impressions of the Congress: Jodi Woodhall

*What a fantastic four days! The opening and closing ceremonies were so inspirational and teary all in one. What effort and time the Congress Committee and workers put in to make this Congress a success. Below are some of my thoughts and reflections from some sessions I attended:*

**“A Family Experience with Autism”** – Leighton Jay, Australia (father with an autistic boy.)

*Here are some feeling words we may experience and feel:*

Frustration	Grief
Trapped	Intense
Exhausting	Tiring
Relentless	Stress

Impact on our lives:

Activities	Outings
Social events	Friendships
Community Events	

*Other words:*

Learning	Limiting
Loss of control	Under-supported
Costly	A major project

*Mr Wayne Gilpin (USA.)*

He has a son with autism called Alex. Wayne Gilpin is the author of **“Laughing and Loving with Autism.”**

He tells parents to:

Enjoy your child

Laugh with your child

Learn to know your child not the autism.

Parents need to be number one experts. Learn your children’s games and get to know their interests!

**“Have a Happy Autistic Holiday”** – Miss Penelope Brennell (also from the USA)

*(Continued on page 6)*

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*Christmas/Birthday parties are less stressful if they are held in your own home. Play your child's videos all day. Set up a table of foods your child likes, and if he/she gets stressed and needs time-out, make sure your child can go to their room for a safe haven. A lot of children don't associate presents being wrapped up in paper. Make it less stressful by just*

*placing presents in a bag. They will appeal more.*

There is no cure for Autism at this stage. There may never be a cure, but it's up to us as parents, as family, as friends and society to make autistic children welcome in our world, and to learn about theirs.

**Jodi Woodhall**

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## Impressions of the Congress: Ros Ward

***Congratulations must go to Autism Victoria for organising an excellent Congress, with superb keynote speakers from around the world. (I personally could have listened to Eric Courchesne, Rita Jordan or Temple Grandin for considerably longer).***

I attended many and varied papers over the four days, but as the parent of a sixteen year old son, I was particularly interested in those aimed at adults and those with an employment or vocational focus. Having been to many national conferences where the focus (not necessarily intentional) has been on high functioning children in particular, it was encouraging to see that agencies and Autism Associations are planning for adulthood.

So what do adults with an autism spectrum disorder need? The following article is my impression of current trends from the papers presented.

At Alpha Autism in Melbourne, a pre-vocational program and the Alpha Employment service operates. This is a small operation, which caters mainly for people with high functioning autism or Asperger Syndrome. The pre-vocational program is "designed for individuals who require a small intensive program to bridge the gap between school and employment options." The Alpha

Employment service is a specialist employment service that places and supports clients in meaningful open employment.

The Autism Association of Western Australia through A.I.M. employment service also aims to match people for employment. However it also has supported enclaves within the open employment market. For example, at the Commonwealth Bank in Perth, a group placement for people with an Autism Spectrum Disorder operates. Ongoing intensive support is provided with an award based wage. There are flexible working hours within the integrated setting. To begin with, the workplace is set up by non-autistic people to put systems in place, (eg visual structures and left to right sequencing). Gradually people with an autism spectrum disorder are introduced into the workplace.

June Waites, mother of Dane and author of *Smiling at Shadows* together with Virginia Fitzclarence from Workability NSW presented a paper highlighting employment within a regional setting. June writes of Dane 's desire for a real job in her book "Smiling at Shadows", but it was extremely interesting to hear the employment agency perspective simultaneously. The paper highlighted how a family and an agency can work

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together to create a successful outcome. Over the years families devise and use many strategies with the person with ASD and June and Virginia clearly showed how those years of family experience can be used to create an effective employment setting.

There are many issues and barriers to employment for people with ASD including, inappropriate social behaviours (need to tailor the job), obsessions (give controlled access to obsessions, be inventive to accommodate the style of the person with autism), organisational skills (use visual timetables to illustrate sequencing and prioritisation), sensory difficulties, unrealistic expectations, personal presentation, sleep patterns, incorrect initial diagnosis or late diagnosis, literacy and numeracy skills, communications skills, desire for socialisation or a relationship. All the papers highlighted how important it is to match the job to people's strengths and to look for jobs that match existing skills. What are the strengths of people with an ASD in open employment? Many are very dependable, reliable and punctual because of the attachment to routines. The experience of those who presented papers at the congress is that people want to work and have meaningful lives and Temple Grandin reiterated this point in her presentation.

Alpha Autism also operates several day programs throughout Melbourne. The focus at these centres includes relaxation, social stories, communication, music and

sensory activities, art and drama, cooking, swimming, budgeting, negotiating, gardening, human relations, computers, meal preparation, banking etc. Not all these activities are available at all centres.

I also attended a paper presented by an agency in Glasgow Scotland, who provide one-on-one care based in the individual's home. This was extremely uninspiring.

So what does all this mean for Tasmania? Mark and I visited the Alpha Employment service following the congress. Our advice from the Manager, as parents living in a regional area, was to keep our son at school for as long as possible!!!

### **Ros Ward**

*Autism Tasmania would like to hear from parents, agencies, people with an autism spectrum disorder etc who have experience in the area of post school options/ employment for people with an ASD in Tasmania. What is currently available in our state? What are the attitudes of employers to people with a disability, in particular ASD? Your thoughts would be appreciated. Please forward to PO Box 1552, Launceston or email to Ros Ward [rosnmark@iprimus.com.au](mailto:rosnmark@iprimus.com.au). We look forward to hearing from you.*

"There is no substitute for the strength parents can give each other"

*Mr Pat Matthews, President, World Autism Organisation*

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## Impressions of the Congress: Scott Woodhall

I think the most inspiring part of the Congress for me was listening to Mr Wayne Gilpin from the USA speaking from a father's point of view. Fathers play a vital role in the life of their autistic child, right from the word go. Mr Gilpin spoke about the joys and heartache of his son's life with Autism. He also spoke about the many therapies he had to use to help his son reach his full potential.

We also learnt about a school for autistic children called Irabina, which is in Victoria. Teaching key strategies was discussed, starting with the need to share. With many children you begin by trying to establish joint focus. To do this you need to target the interest of the same age peers but try not to make it repetitive.

Swapping versus sharing was also discussed, that is the need to introduce the concept of trading before the concept of sharing, and sharing needs to be made as easy as possible when introduced to the child.

Turn-taking – this process is taught with visual support by using photos of the children involved. Play can also be taught with visual sequences using photos.

We also learnt about interactive music ideas for children with Autism and Aspergers Syndrome. Music Therapy is the planned and creative use of music to facilitate positive change in the life of an autistic or Asperger person. What actually happens is children play different sorts of musical instruments or dance and do body movements to various types of music. All sessions are very well structured. Their main goal areas are:

- Communication
- Emotional and social skills
- Movement and sensory integration
- Cognitive skills

There were also a lot more interesting sessions we attended. What we got out of the Congress was very helpful and has given us hope for the future of Zachary and other children with Autism. I hope this has given you an insight into the world of autism and what we learned as parents.

**Scott Woodhall**

I would like to acknowledge Autism Tasmania for arranging funding for my registration costs at the Inaugural World Autism Congress which was held November 2002 in Melbourne. The Congress took awareness for ASD to new heights.

It was memorable to participate in such a high class event and absorb the latest research and personal viewpoints presented. Another most enjoyable highlight of the Congress was making new friends from around the world and learning about the supports set up for people with ASD in their community.

I was also proud to listen to two presentations from our own state of Tasmania. One from the government described an Autism Support Network for parents and professionals and the other from the private sector had one of the latest developments in therapy to describe about developing desire in children with ASD to socialise.

**Rosemary Rush**



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## Early Childhood Intervention Conference

### HOW PROFESSIONALS CAN AFFECT THE OUTCOMES FOR OUR CHILDREN by Lisa Minchin

*On September 28<sup>th</sup> 2002, the Early Childhood Intervention Conference was held in Hobart. ABIT (Autism Behavioural Intervention Tasmania) presented "How professionals can affect the outcomes for our children." We are publishing the introduction by Lisa Minchin and one of the stories that followed. Both the authors are parents of children with an Autism Spectrum Disorder and are also members of Autism Tasmania.*

Autism was first clinically recognised just over 50 years ago.

Initially it was believed to be caused by poor attachment between mother and child. This view led to the coining of the term "refrigerator mother" and so the early therapy developed by professionals consisted of psycho therapy FOR THE PARENTS to help them connect better with their child.

Sadly, such therapy has been suggested fairly recently to one of our members.

It can be argued that Autism is a "stand alone" disability in that the needs of children with autism are quite distinct from other children with disabilities....this fact obviously has implications for professionals.

Autism affects

1. communication – both verbal and non verbal
2. social interaction
3. play

These impairments mean that children with autism have major difficulties in development as it is so hard for them to learn naturally from their environment.

Our group recognises the critical role of early diagnosis and intervention for

children with autism and it is our belief, supported by research, that these children will be served best by intensive, autism-specific intervention. This intervention will engage and assist our children to build socially useful skills and improve their academic performance.

Compared to other disabilities, autism alone clearly benefits from a high level of intensity of therapy.

Research also shows that parent training and involvement in therapy is instrumental in affecting outcomes in the child's development.

What will emerge from listening to our stories is that there is still a significant need to raise awareness of autism - at playgroup level, in childcare centres, at clinic checks, with General Practitioners, indeed with paediatricians as well as with family and friends. Many of these key individuals will be loathe to be the first to acknowledge that there is indeed a problem. But parents must be encouraged and assisted with the first steps to getting help!!

The professionals involved need to be direct and open yet compassionate in expressing the need for and directing a referral.

On-going autism-specific professional development is vital – professionals trained more than half a decade ago will have very low expectations for our children and we all know the dangers of self-fulfilling prophecies.

The professionals working at the various agencies involved need to have clear lines of communication and need to

*(Continued on page 10)*

*(Continued from page 9)*

maintain continuity of communication. There is also a need for the establishment of clear protocols for action – especially when it is urgent.

Diagnosis is a vital area – in autism the sooner the better - so that children will benefit most while their brains are at their most receptive and flexible.

We'd like to see professionals being more confident and unafraid to commit to a diagnosis – or at the very least to openly recognise at the first opportunity that there is a specific concern that needs to be checked out. We want to see professionals more “up front” when discussing diagnosis with the family and to share information that will be comforting and give direction after the appointment has ended.

Professionals have a challenge in balancing the need of parents to have time to grieve against the fact that these children need to commence appropriate treatment as early as possible.

Speaking as a parent and with hindsight, I'd say PLEASE put the child first!

Professionals need to be well informed about the worthwhile treatment options that are available and to have written objective information to pass on to parents about the choices they can

make.

Professionals need to provide on-going support and advice when needed – many of our members felt cast adrift after that initial diagnosis ...or professionals could refer these parents immediately to a support group such as ours so that terrible post-diagnosis isolation can be avoided.

At all stages in the process, there needs to be healthy communication between appropriate agencies and mutual respect between team members, and parents MUST be regarded as key members of the team as they are the experts on their child.

Throughout the child's life, families require the on-going help of committed professionals.

We would also urge parents to trust their instincts and to listen to other parents further down the track who have already been there and done that.

**Lisa Minchin.**

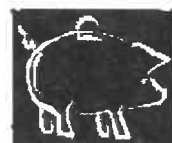


## **Autism Tasmania Inc**

**HELP!! We need people to sell buttons for Autism Tas on Friday May 16th in your area.**

### **Autism Awareness Week**

Information and Seller's Kit supplied  
Phone Rose Clark for details on 64 231086



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## HOW PROFESSIONALS CAN AFFECT THE OUTCOMES FOR OUR CHILDREN by Anne Wilmshurst

Our third and youngest child is a young man who will be eighteen next month. He was diagnosed as being on the Autistic Spectrum when he was 14 ½ years old. The late diagnosis meant that he missed out on vital intervention that could have helped him as he was growing up and prepared him for adulthood more appropriately. His personal development was marred because of the unremitting stress he suffered. He became very angry, reactive, withdrawn and uncooperative with anyone.

In 1988 when we first started consulting with professionals, and our son was aged 3 years old, there wasn't much awareness about High Functioning Autism or Asperger's Syndrome.

By 1999, when our son was given a provisional diagnosis of High Functioning Autism it took a foreign, visiting doctor to make those observations. It then took another year and a psychologist visiting from interstate to give a firm diagnosis of Asperger's Syndrome and deliver positive recommendations for his care.

Our son's behaviour was puzzling and difficult. We sought and followed the advice of professionals and read books about learning difficulties searching for solutions. Our lack of awareness of Autistic Spectrum Disorders led to us inadvertently doing many unhelpful things to our son that severely compromised prospects for a good outcome then and later on.

When he was very young he told us during his tantrums that he wanted to die and he tried to commit suicide when he was in year 7. He often threatened to commit suicide. We did our best to cope with frequent, severe and very long temper tantrums as he attempted to control his environment.

We sought help, and it didn't come until he was 16 ½ years old when Disability Services granted our son a unit to live in independently as the situation at home was untenable and dangerous.

In our struggle to help our son we saw a total of 17 professionals before meeting one who gave us an explanation for our son's behaviour that made sense. Up until then he had been diagnosed with separate learning disabilities, Attention Deficit Hyperactivity Disorder, Oppositional Defiant Disorder and Conduct Disorder.

We encountered many professional persons who performed their duties well and displayed genuine concern for our son but were unable to aid us by delivering a diagnosis or appropriate early intervention. The professionals who fitted this category were those who delivered speech therapy, occupational therapy, physiotherapy, vision therapy, special learning services as well as many of the school teachers our son had.

Many other professionals we encountered seemed not only to have been grossly ignorant of Autistic Spectrum Disorders, but also extremely arrogant in their ignorance. We encountered this amongst paediatricians, psychiatrists and psychologists.

For example:

1. Blaming the mother for the child's troubles and thereby overlooking the need of the child for intervention and management at a crucial stage.
2. The expressed attitude that a diagnosis is not necessary as we would be burdening our son with a label for the rest of his life. This attitude stopped appropriate intervention happening.

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*(Continued from page 11)*

3. The only treatment the paediatricians we saw offered, besides psychological counselling through their approved psychologist, was the prescription of medication to quieten our son's behaviour – medication like dexamphetamine, Ritalin, Prozac, Luvox and Risperidone.

4. We found the practice of paediatricians being overly reliant on psychologists to administer psychological testing for their patients, pronounce a diagnosis and deliver a management plan for that patient to be problematic.

We consulted a paediatrician and went through the process of seeing the psychologist and having our son tested. A diagnosis was given, with advice to the doctor and us. We were expected to continue seeing the psychologist for repeated sessions of counselling to aid us in our son's management. The psychologist's influence extended to advising the doctor to continue using the medication he was already prescribing and that he not do a home visit to see our son otherwise he would be rewarded for his oppositional behaviour. Visiting our son at home would have been the only opportunity available to the doctor at that time to observe him.

The psychologist changed her diagnosis of Oppositional Defiant Disorder to Conduct Disorder because our son's behaviour did not meet societal norms in a more serious way than previously i.e., he was tantruming more and more withdrawn. The psychologist repeatedly told us that our son must attend school and that if necessary we must demand that the police take him to school. She advised us to make him do what we told him to do and take control of the situation. Her advice only worsened his stress, withdrawal and hostility.

The psychologist asked me, when

putting together her final report about our son, if I thought he was autistic. I replied that I did not think so because he did not fit my concept of autism which was an extremely limited one. She responded to my completely ignorant assessment with her agreement.

There have been many incidents of professional ignorance and ineptness that have occurred to our son besides those I have mentioned. I chose to describe some instances that happened at extremely formative times for him.

We attempted to get our son to finish high school but he never completed years 7, 8 or 9 before he dropped out. He is living independently now and his stress has been greatly alleviated and so has ours. He still leads a rather isolated life, is difficult to interact with and has need of support. We do not know whether he will ever work.

I am absolutely certain that an early intervention program that was suited to our son's specific needs as he was growing up could have ensured he adapted to life in a much better way. He needn't have found school and family life so traumatic if appropriate consideration and adjustments could have been made for him. All of this could have happened if the professionals we consulted were aware of the symptoms of High Functioning Autism and Asperger's Syndrome.

**Anne Wilmshurst**

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## Parent line – Practical Solutions

### LEISURE OPTIONS.

*Established in 1987, Leisure Options has undertaken holidays within Australia or overseas for people with disabilities since 1993. They cater for people with a disability and older adults. They provide a supportive holiday environments and high staffing ratios and a commitment to individual needs and interests.*

They tailor programs to an individual's skill level, needs and interests. This includes programs for:

- People with a mild intellectual disability and/or developmental disability;
- People with severe or multiple disabilities;
- People with physical disabilities;
- People with an intellectual and/or developmental disabilities who are frail;
- People with an acquired brain injury;

- Older adults (frail aged);
- Individual programs; and
- Children with a disability.

They also provide a holiday and travel booking service for people with disabilities, their families and their carers – **thoroughly recommended (by one member of ACD) who has used this service.**

**ACD is Association for Children with Disability.**

*For more information;*

*Ph (03) 5222 3738*

*Fax (03) 5222 3373*

*Freecall 1800 801 250*

*Email [mail@leisureoptions.com.au](mailto:mail@leisureoptions.com.au)*

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## QANTAS Carer Concession Card

### ***Great news for people with a disability travelling by air!!!***

The Qantas Carer Concession Card is issued to people with a disability and high level support needs, who require the full-time assistance of a carer whilst they are on the plane.

- **A person is eligible** if they need to have one-on-one support when seated on the plane and for tasks such as feeding, transferring to the bathroom, communicating with airline staff etc.
  - **A person is not eligible** if they only need assistance boarding the plane, or when they arrive at their destination.
- Cardholders receive a 50% off the

standard full price of domestic air travel, in addition to 50% off their carer's fare. The Carer Concession Card does not apply to already discounted fares or 21 days in advance fares. The card will not reduce a child's fare further, but will reduce their adult carer's fare by 50%.

The Carer Concession Card is a photo ID card, which is valid for 3 years. It has an administration fee of \$27.50 including GST.

***For further information contact the National Communication Awareness Network (NICAN) on 1800 806 769***

### SHAVING PROBLEMS

#### Advice on shaving those with an ASD

***I used to have real difficulty shaving my 19 year old son Matthew. I would end up 'handcuffed' by his strong grip of protest each time I held a shaver close to his face and shaving was a real nightmare. But.....I have got the victory YEAH!!!! Perhaps this solution may help someone else having the same difficulty.***

In a nutshell, Matthew's problem; Hypersensitivity plus to some sounds and touch.

*Solution to problem;* now I use a massage vibrator for each shave, to desensitise and prepare the skin for the shaver. I begin by putting the vibrator on his hands and then when comfortable with it's sensation there, I then use the massage vibrator on his lips, then cheeks, then by his ears and finally under his chin.

The order of vibrations is from Matthew's lowest degree to his highest degree of sensitivity. Once I've done this I quickly move in with the shaver and 9/10 times I now have no resistance, *but* total co-operation. Hoping eventually to move from co-operation to independence.....eventually.

For the 1/10 times when there is still resistance I don't argue, I just say 'I think you needed the vibrator for a little longer', and do another few minutes vibration therapy. We have thus far had full co-operation, and no battles since I've used the massager. I have the massage vibrator set on a 'warm vibration' setting and I spend about 3 minutes using the vibrator before shaving.

To help with regard to his sound sensitivity problem, I took him into our local shop that sells shavers and

explained to the assistants Matthew's sound sensitivity problem. He turned some shavers on so Matthew could choose the one he liked best. The assistant was very helpful and Matthew listened to 6 shavers in total and chose the quietest and most pleasant sounding one to him.

I would have used this fact as ammunition against any protest by Matthew should he have resisted the shave because of the sound factor again, but he did not. The assistant by the way was astounded at the difference in sounds of different shavers and he was keen to know a little about autism, so, he was absolutely thrilled that we visited him that day, (apart from the fact that Matthew chose the most expensive shaver).

It has been most worthwhile though, and now my day does not begin with "Oh no! the shave" and a dive for an extra cup of coffee to brace myself for the 'shave'.

(Massagers can be bought at some Chemist shops and Electrical Appliance Stores. The one I use has a large flat head on it).

Written by **Lesley Schwass** (Matthew's mother).

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## AUTISM ASPERGERS ADVOCACY AUSTRALIA

*Autism Aspergers Advocacy Australia, a new national autism lobby group, held its first briefing at the Melbourne Convention Centre, in conjunction with the Inaugural World Autism Congress. The meeting included a comprehensive briefing about the role and aims of this new organisation, and over 200 Congress delegates and visitors attended.*

The A4 Convenor is Judy Brewer Fischer. She explained that A4 is:

- A national grassroots organisation
- An email based information network
- Focussed on the development and promotion of national Autism Spectrum Disorder policy priorities
- Concerned with the 'big picture' issues
- Activities are likely to be Canberra based
- Closely affiliated with the Autism Council of Australia
- A small step in a long, long process

Judy emphasised that A4 **is not:**

- An autism support group
- A protest group
- Advocacy at the State or Territory level
- An email chat forum
- A cure for autism

The meeting wholeheartedly agreed that what is needed is a national action plan for autism and it is needed NOW!!!!

A steering committee was formed and the first A4 activity announced. It will be –

**Canberra Adventure 2003** – Friday May 30 to Tuesday June 3. The A4 'Walk on Canberra' is likely to be June 2<sup>nd</sup> and 3<sup>rd</sup> when Parliament is sitting.

To contact Autism Aspergers Advocacy Australia send an email to [aaadvocacy@bigpond.com](mailto:aaadvocacy@bigpond.com)

**Promotional Film** – A4 is developing a promotional film. Autism Victoria member Rebecca Albeck is producing the film and needs volunteer families. She has sent in the following request:

***VOLUNTEER FAMILIES NEEDED*** to participate in the making of a short film publicising the needs of individuals and families affected by an Autism Spectrum Disorder. This promotional film will be used by the newly launched **A4 Advocacy Group**. The aim of the group is to increase awareness and understanding of Autism Spectrum Disorder and lobby our politicians and communities to provide more support for families living with the challenges of Autism Spectrum Disorder.

Please contact Rebecca on 0411 454 024 or email [ralbeck@hotmail.com](mailto:ralbeck@hotmail.com) if you are interested in participating.

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*Enclosed in this mailing is a application form for A4 membership.*

## Autism News

The newsletter of Autism  
Tasmania Inc.

Postal Address  
POBox 1552  
Launceston  
Tasmania 7250



Providing lifelong support to  
people with Autism and related  
disorders.



## INAUGURAL WORLD AUTISM CONGRESS COMMUNIQUE

*The following statement was prepared for Congress delegates to use in their own communities and is on the Congress website at [www.autismcongress.com](http://www.autismcongress.com) Please use this communique – it belongs to the whole Autism Spectrum Disorder community.*

The theme of this Congress is *Unity through Diversity*. Four groups of people with diverse points of view have come together – people with autism, academics and researchers, parents of people with autism and professional staff involved in service provision. Considerable unity of views has been established both within and between sessions in what has been a positive and very friendly atmosphere. It is apparent that the voices of parents and people with autism themselves are being heard to an increased degree. Parents have had the opportunity to express what it was like to parent a child with autism.

We wish to summarise the deliberations in a Congress communiqué. The communiqué includes a statement of problems and proposed solutions, and is as follows:

### **The main problems identified are:**

- Services are ad hoc, insufficient and ineffectual
- Parents are waiting up to a year and sometimes more for a diagnosis
- Once diagnosed, people with autism often wait a year or more for access to early intervention in the case of young children or other relevant services for older children, adolescents or adults, receiving limited support in the meantime.
- People with autism and their families in remote areas are worse off
- Educational services need to be bolstered by out of school support to families including respite, recreational and family support.

### **What we need are:**

- Proper collection of data on numbers of people being diagnosed and numbers of people in the community with autism
- Diagnosis at the earliest possible stage
- Immediate access to effective early intervention or other appropriate services once diagnosed, with no waiting periods
- Adequate support in regional and remote areas
- Individualised funding on a national basis

This will be the basis of future approaches to community leaders and government representatives following the conclusion of the Congress. Our collective aim is to ensure the appropriate support is provided to people with autism and their families.