



# *AUTISM NEWS*

**Newsletter of Autism Tasmania Inc.**

***Postal Address***

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Launceston  
Tasmania 7250  
Australia

Edition 38  
March 2002

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## BRANCH BUSINESS

### **From the President**

The visit of Junee Waites, author of *Smiling at Shadows*, was a great way to kick off the year. She informed and entertained throughout the State at a variety of venues and was extremely well received. A big "Thank you" to those who attended her sessions.

The Executive and Committee would like to thank you for your continued support and are working towards providing a strategic plan for the future direction of the organisation. To this end we are continuing to assess where we are, where we would like to be and strategies to get there. The committee meeting on the 23<sup>rd</sup> of March has been in part set aside for focus on this. As you would be aware, because of the volunteer status of all members and the restraints that imposes, it is essential that we prioritise our goals in order to achieve some of them well. Committee meetings are open and we are happy for any member to attend, so please contact me and I will let you know the date and venue of the next meeting if you wish to attend - and please don't hesitate to call with any queries or concerns.

As in all organisations the concerns of financial stability are of paramount importance and as part of our focus for the future we are also looking at our financial viability. Our ultimate aim of employing a support worker and advocate to work on behalf of the members is not an impossible dream, but will require a financial long term plan in order to maintain the position long term.

It is with regret that we have accepted Paula Barnes resignation from the committee due to personal reasons. Paula has been a member of the committee and/or an active member of the Autism Tasmania community since the early days and she has continued to tirelessly work for the good of all members. We will miss her off-beat sense of humour at committee meetings but we know that she will always be a staunch supporter of the organisation; and no doubt we will call upon her for advice and help in the future. On behalf of all members of Autism Tasmania, "Thank you Paula"

Regards  
Rachel Hodge

### **Smiling at Shadows**

Author Junee Waites visited Tasmania in February combining a holiday with some engagements for Autism Tasmania. Her itinerary was large and Junee entertained and enlightened wherever she went.

Rosemary Rush and members of ABIT ably organised a speaking engagement in Hobart that was well received by all. A dinner engagement at Launceston was held at Fiddlers Brassiere (highly recommended!) and was followed by an informal coffee and chat afternoon at Giant Steps. Presentations to Rotary, Probus Clubs and Family Respite Care on the North West Coast were organised by Rose Clark. Junee was also heard statewide as she was on ABC radio as well as appearing in *The Advocate* newspaper.

Junee's quiet and dignified style caught the attention of everyone and lifted the profile of Autism while developing understandings and knowledge. Junee and husband Rod managed to find the fine balance between presenting information and entertaining us, through discussing the difficulties and joys of their family life.

Junee's book *Smiling at Shadows* can still be purchased from Autism Tasmania. For those who have ordered books, and have yet to receive them, please contact Rose Clark on 6423 1086 .

## Committee Members of 2002

<b>President</b> Rachel Hodge	molly@microtech.com.au	6344 3261
<b>Vice Presidents</b> Sue Thorogood Eileen Prunster	ThorogoodSue@aol.com Eprunster@yahoo.com	6262 2698 6436 3230
<b>Secretary</b> Cheryl Scott	cscott1@vtown.com.au	6344 8015
<b>Treasurer</b> John Christie	jandme@qctas.net	0418 657 492
<b>Committee</b> Rose Clark Rosemary Rush Maurice Hogan, Amelia Bishop	micknrose@vision.net.au rushm@netspace.net.au mhogan@vision.net.au akenny1@vtown.com.au	6423 1086 62 295760 63 265598

## **CRC FUNDING (Commonwealth Respite For Carers)**

Each year, Autism Tasmania receives funding to provide respite for carers to attend functions related to the care of their child who has Autism. This is where Autism Tasmania contributes \$12.00 per hour to the cost of your choice of child care during that function

Eligible activities include:

- Attending autism support meetings
- Case Conferences
- Meetings at school/IEP sessions
- Workshops seminars

We have had difficulties using all of the money in this financial year and we stand to lose a portion of this funding next year. As a result, the committee will be applying to have the terms of use broadened, so that we can use it for things like Emergency respite and more general professional development activities for members.

Until we make a new submission and reach a new financial year, we are only able to spend the CRC money on the above list.

If members have participated in eligible activities in this financial year, retrospective reimbursement may be possible. If you would like to make a claim, please contact Rachel Hodge, who can advise you.

Listed below are some activities, which may be of interest to our members, that would be eligible for CRC funding.

We also hope to run a professional development activity during Autism Awareness Week in May. This will be an excellent opportunity to families to access this Commonwealth money.

Cheryl Scott (Secretary)

THESE FUNCTIONS ARE ALL ELIGIBLE FOR CRC FUNDING

### **FOR YOUR INFORMATION**

Fri APRIL 19 Bowen Support School Clarence Street, Howrah 9.00 –4.30	<b>From Toddler to Teen Managing the Emotional Development of a Child with ASD</b> <i>presented by Jura Tender BA, B Ed, M App Psych</i> at Contact Intervention Services for Autism & Developmental Delay	www.isadd.org contact Peta Kelly 6265 9008  Cost\$90.00
Sat/ Sun APRIL 20,21 Tramsheds Launceston 2 day workshop	<b>Picture Exchange Communication (PEC) Workshop</b> <i>presented by Sue Barker Clinical ED Psych and Catherine Silcock SLP B.Sp Therapy</i> sponsored by Pyramid Education Consultants Australia	info@pecs-australia.com www.pecs.australia.com ph 08 8331-7727 fax 0883317757 Costs:Professional (\$385) Student/Parent (\$220)
Mon Tues APRIL 22/23 Morning and afternoon sessions Sat APRIL 27 All day Hobart Venues to be advised	<b>Resilient Learners, Resilient School, Resilient Young People</b> <i>presented Andrew Fuller Clinical Psychologist</i> Addresses approaches to specific issues such as anger, aggression, bullying, depression and suicide, self harm nad problematic substance use	Contact 6228 9144 NSDEP State Co-ordinator Esme Merphy at esme.Murphy@education.tas.gov.au  <i>NB Andrew Fuller will be speaking in the North and NW later this week</i>
Mon APRIL 22 Salamanca Inn Tues APRIL 23 The Gateway Inn Wed APRIL 24 Matsons Function Centre 9.30– 3.30	<b>Managing Challenging Behaviours</b> <i>Presented by Clive Dennis RMDN, B. App Sci (DD) Master of Special Ed</i> A workshop to provide options to parents, teachers and others to prevent and /or reduce the possibility of Challenging behaviours in both Children and Adults.	Contact Special Education & Disability Services 08 8288 7511  Cost \$143.00
May 12 –19	<b>Autism Awareness Week</b> Social function/s – Professional Development functions – Button Day (Friday)	Details to follow

## **WORLD AUTISM CONGRESS 2002 – November 10<sup>th</sup> - 14<sup>th</sup> 2002 Melbourne Convention Centre.**

The Inaugural World Congress will truly be an international event of great value to anyone interested in Autism. Online Registration for the Congress is now open via the web-site – [www.autismcongress.com](http://www.autismcongress.com) The program for the congress is coming together and invitations for Plenary Presenters were issued around the world. The organisers are pleased to announce the following Plenary Presenters;

Dr Eric Courchesne – Children's Hospital Research Centre, San Diego, California, USA

Dr Yoko Kamio – Centre for Clinical Psychology & Human Development, Kyushu University Japan

Ms Donna Willilams – Autism Consultant and author, United Kingdom

Ms Wendy Lawson – Autism Consultant and author, Australia.

Dr Rita Jordan – World renowned speaker and author of many publications in the field of Autism, United Kingdom.

**Keynote Speakers** for each Topic Stream and Focus Area will be drawn from among the many Presentation Proposals. Keep an eye on the Program section of the Congress web-site, as the program of speakers and presentations develop this section of the web-site will be updated.

### **CULTURAL EVENTS DURING THE CONGRESS.**

The Exhibition Hall will be a popular venue during the congress. As well as housing the many Poster Presentations, refreshment bays and commercial and service agency displays, the World Autism Congress Art Exhibition will also be featured. Whilst most exhibits in the Art Exhibition will be the work of local artists with an Autism Spectrum Disorder, a group of US parents will be sending items for the exhibition. If you would like to offer an exhibit, please email the Congress Secretariat at [enquiries@autismcongress.com](mailto:enquiries@autismcongress.com) with details of the artist and the proposed exhibit (s), You will be contacted by a member of the Art Exhibition organising team.

*Spiegel the Cat* is a musical interpretation of a 19<sup>th</sup> century Gottfried Keller story from *The People of Seldwyla*. Writer David Martin and composer Wendy Hiscocks have developed a story of great wit and charm about the disadvantaged overcoming the odds. *Spiegel the Cat* will be staged from 13<sup>th</sup> – 16<sup>th</sup> November 2002 to coincide with the World Autism Congress.

## **THE AUTISM COUNCIL OF AUSTRALIA**

At recent meetings of the Autism Council of Australia it was concluded – *that if government can't be persuaded to assist in the establishment of a professional secretariat, we will have to do it for ourselves.* Currently delegates to the Council, (who come from state associations) run the secretarial/organisational component of the organisation as well being involved in their own organisations.

The Autism Association of NSW brought a very generous offer to the table. From part of the proceeds of a recent substantial bequest, they were offering 50% of the estimated cost of employing an Executive Officer for the Autism Council of Australia for up to 18 months, as well as providing office facilities in Sydney. Each of the other states were asked to contribute the remaining 50%.

The Executive Officer will be required to source funds to make the position self-funding within 18 months, with most funds probably coming from the corporate sector. The Executive Officer will have lobbying federal government as part of their brief, as well as developing a National Autism Awareness Strategy.

This is the autism community's big opportunity, and most state governing bodies have recently voted in principle support for the proposal. Being prudent organisations, they are insisting that care is taken to ensure that the objectives are achievable, and that our valuable and scarce funds are well used.

Rose Clark

### **Don't forget!**

Subscriptions for 2002 were due at the end of December

This will be your last newsletter if you have not renewed by Easter

## WHAT'S BEEN HAPPENING

### REPORT FROM ABIT - AUTISM BEHAVIOURAL INTERVENTION TASMANIA - FORMERLY YAST

The ABIT year got off to a great start with the family beach day at Cremorne in mid-January. Many old friendships were renewed and new family friendships begun. We were very pleased to host a night with speaker, author and mother June Waites of "Smiling at Shadows" who addressed a very receptive group of listeners at the Chorus Hotel in late January. ABIT is most grateful for the support of Autism Tas in facilitating this visit.

Our February support night was held at Sal's cafe/restaurant/bar in Salamanca Place on February 20 and it was good to see some new faces along. Our next support night will be (as always) on the third Wednesday night of the month, March 20 at Anita Killick's home at 73 Pedder Street, New Town from 7.30 pm.

The details of our April, May and later support nights haven't yet been finalised but they will be held on the third Wednesday of the month, that is April 17th and May 15th. We will mail out information to financial members as soon as possible.

Disability Discrimination solicitor Judith Blades will be in attendance at our April 17th meeting at Lisa Minchin's place, 4 Lasswade Avenue, Sandy Bay from 7.30 pm. (Please RSVP 62 232317 and feel free to bring a plate!!!!) Judith will talk about her work but most importantly she wants to hear our individual stories of inclusion ....Come and share and listen and feel supported knowing that there is much strength to be derived from being part of an active group that will lobby on behalf of the children and families we support. I have seen Judith in action and her knowledge and presence is MOST impressive!

Remember our support nights are just that, support and information and understanding listeners. We are in the process of organising some

speakers for some of our information nights and are liaising with ABA groups in other states to try to bring some outstanding speakers to the country later in the year if possible or at the very least to tap in to the pool of ABA speakers who attend the World Autism Congress in November.

Many of our members will be attending the Jim Partington seminars to be held in March by ABAKidz. We are very grateful that they have taken this initiative as the opportunity to hear a world renowned expert on language development will be of benefit to us all.

Our open committee meetings are held separately from support nights as that is what many of our members requested. If you would like to be part of active committee work, don't hesitate to give me or one of our committee members a call. All the best to you all and your families and those you care for.

Lisa Minchin, President, *phone 62 232317*

## Deadline 25th May

*The deadline for the next issue of Autism Tasmania will be 25th May. Please forward your copy to Cheryl Scott on [cscott1@vtown.com.au](mailto:cscott1@vtown.com.au) or phone 63448015 a.h. to make alternative arrangements*

## Disclaimer

*The opinions expressed in this Newsletter are those of the writer and do not necessarily reflect the views of Autism Tasmania Inc.*

*Any mention of products or treatments does not constitute an endorsement.*

*The Editor reserves the right to follow normal sub-editing procedure.*

## GIANT STEPS TASMANIA

Focused professional development is always a high priority in organizations which aim to keep up to date with what's happening in their field of operations. Autism Education is no different from any other educational endeavour in that research is on-going and new techniques are forever unfolding.

Elsewhere in this newsletter you will find a summary of the main interventions which are being used today across the world. At Giant Steps, we use elements of all of these but, in recent years, have become more and more attracted to the TEACCH program which, more than any other seems to address the individual needs of the autistic person at every stage of their lives, while being flexible enough to accommodate different approaches as required.

Last year, our therapy team was fortunate enough to meet Polly Yarnall, one of the United States' foremost autism educators, during a visit to Tasmania and we began to make plans then to bring her back to the state to work in some depth with our staff. On her visit in February, she presented a three-day workshop to the staff, then worked for a further two days in the classrooms, helping to put in place the ideas which have been proving so effective across the United States and Great Britain. A small group of parents and teachers were also able to hear Polly at a one-day seminar in Launceston.

She began her Giant Steps workshop with a summary of the most recent research into the neurology of the autistic brain. Modern techniques allow researchers to identify subtle differences between the brains of autistic and neuro-typical people and the findings of this research not only help to provide answers to the questions of why autistic people behave as they do, but also give pointers to how they learn and how best we can teach them.

We had asked her to focus in her talk on the Structured Teaching approach which underpins the TEACCH schools' programs. Structured Teaching has five important components:

- Organizing and simplifying the physical environment to be more consistent with the ways that people with autism process sensory information
- Developing meaningful schedules to make each day more predictable

- Developing individual work systems for independent functioning so that students always understand how long they will be working on tasks and when they will be finished.

- Using visually clear and meticulously organized materials, and learning to identify and use visual cues, so that they can facilitate generalization.

- Establishing positive and productive routines.

Polly believes that structure to an autistic person is like a hearing aid is to a person with a hearing disability – it is a prosthesis, compensating for a deficit. And, just like a hearing aid, we don't remove it over time. Structure is blended into their lives so that the student understands how to look for the visual information in different environments. The goal is for the student to develop ability to function as independently as possible in the community.

Polly will be back in Tasmania on a regular basis. We are keen to develop a long-term relationship with her and foresee that she will be invaluable in maintaining our contact with the wider world of Autism education.

John Christie  
Principal

### AUTISM SUPPORT GROUPS IN YOUR REGION

**Autism Southern Support Group**  
Contact Janet Smith on ph. 62591149

**Autism Northern Support Group**  
Contact Sue Thorogood on 63622698

**Autism North Western Support Group**  
Contact Rose Clark 64231086

**Autism Platform**  
Paula 6397 3088



## FEATURE ARTICLES

### SIBLINGS

The following is from an article, the complete version of which can be found at: [www.parenting.sa.gov/pegs](http://www.parenting.sa.gov/pegs)

When a child has a disability it affects everyone in the family including the brothers and sisters. How brothers and sisters react to having a sibling (a brother or sister) with a disability can depend on the kind of disability, their age, the age of the child with a disability and how it is managed in the family. *Most importantly it will depend on how parents manage and the support they get from their parents.* Brothers and sisters can have some of the same feelings of loss that parents have. It is important that their feelings are heard and understood. Brothers and sisters can also have a lot of joy from their relationships with their siblings with a disability, and learn a lot that will help them develop into caring, non-judgmental young people.

#### DIFFERENCES FOR BROTHERS AND SISTERS

Some of the differences for brothers and sisters of children with a disability are:

- Family life may need to be arranged differently to allow for the treatment and training needs of the child with a disability.
- Family outings and activities (where the family can go as a family) can be affected
- Other children in the family may miss out on time and attention from parents, and feel jealous of this. Sometimes brothers and sisters fight between themselves because they know they cannot fight with the child with the disability.
- Children may feel guilty if they complain because they are expected to be sympathetic, or if they do not want their sibling to be with them when they are with friends.
- Children may feel afraid of what the disability means to them. They may not understand that they cannot catch it.
- When their friends come around they may be embarrassed by their siblings behaviour.
- Sometimes brothers and sisters may be asked to act as carers to help their parents out.
- They maybe worried and upset by parents' re-

actions to the problem, especially if parents are grieving or fighting (which can happen under stress).

- They may feel pressure to succeed to make up for the parents' disappointment.

#### WHAT SIBLINGS SAY

This section has some of the issues that have been raised by brothers and sisters, with some suggestions for what you might do to help them.

*"People ask what it is like to have a sibling with autism."*

The brother or sister can answer something simple but truthful. Some examples could be the following.

- "Normal – I have never known anything different."
- "It can be a pain sometimes. But so can my other brothers and sisters."
- "She is my sister, not just someone with a disability."

*"I am afraid that when my parents die, he will be my responsibility."*

- While you hope that brothers and sisters will always care for each other, you need to make provision as far as you can, for your child with the disability so there is not an unfair burden for the siblings.

- Talk through this issue with your other children so you can hear their fears and talk about what can be done to plan ahead.

*"I hate asking my friends over to play because he always joins in and spoils the game."*

- Let the siblings know that they do not always have to include the child with the disability, just as they will not always want to include each other. This is especially important in the teenage years.

- Set up a place for the child with the disability with some special activities eg; a video or TV, for when the other children have friends over.

- Some active children with a disability can be happily occupied on a swing so the other children can play together.

*"I always feel I have to explain to my friends that*

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*it is not genetic, it is not part of me and it is not catching."*

- Some conditions are genetic (run in the family) and some are not.
- Give children very clear information about the condition.
- Even genetic conditions do not affect everyone in a family and will not necessarily affect the children of the brothers and sisters.
- Get genetic counselling for the brothers and sisters if necessary, as they grow older.

"I can never have my party anywhere I want to because she has severe asthma and these places would make her ill."

- Children and young people should be able to have their special occasions with their friends.
- Some families have two birthday parties - one for the family where everyone can go and one just for friends.

"My sister always gets the biggest part of mum's time and she gets away with everything because she's got problems."

- It is important to try to make time for all the children, even if it sometimes means getting respite care or help with caring for the child with the disability.
- All children will test limits and it is not helpful for any child to have unfair allowances made as children with a disability will fit in best and be more accepted if they are able to conform with the behaviour that is expected of children. On the other hand the other children need to know that you can only expect what each is capable of and that will differ between children.

*"My friends sometimes call people 'a spastic' when they want to put them down. My brother is 'spastic'.*

- Children may need help to cope with situations like this, where the friends may not be meaning to tease.
- They could reply by saying what spastic (or whatever word is used) means, and that it isn't fair to tease people who can't hold their own.
- If friends actually make fun of the child with a disability the sibling might say something like "He does have some problems, but he is really good at...." Or "Everyone has problems. He is my brother and I feel sad

when you tease him."

- Bullying is not OK and should not be tolerated. Sometimes a brother or sister can help, eg one sister used to say "My sister was born like that, what's your excuse?" – which make the teaser stop and think.

*"I have to care for my brother a lot when my mum is working because he has cystic fibrosis and is in a wheelchair, and I can't play with my friends."*

- Brothers and sisters of a child with a disability sometimes have to carry extra responsibility, especially in single parent households.
- This responsibility can help them to be more independent and have more skills that other children of their age.
- On the other hand all children need time to be children so it is important to make sure they get this, even if you have to get someone else to care for some of the time.
- Some children do not say when they feel overburdened or may feel guilty if they complain, so it is a good idea to check how they are feeling from time to time.

*"I often feel disappointed, because when my parents plan something for me, something goes wrong for my sister and we all have to go to the hospital."*

\*If planning is a problem in your family because of the health needs of one of your children, try to work out an "in-case" plan....in case we can't go to the pageant, in case something goes wrong when it's your party....These plans could include the support of a special aunt or other relative so the celebration does not have to be missed, or perhaps an alternative time for a special outing – work it out with your children if they are old enough.

*"I am always expected to be the responsible one, to give in when there is an argument."*

- It is not good for any children to always get their own way and children and young people with disabilities also need to learn to consider others as well as they can.
- Teaching your child who has a disability that she cannot always have her own way, and to behave in ways that fit in with the rest of the family will make everyone's life easier.

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## WHAT YOU CAN DO

- Every child in your family is important and needs to feel special and valued. Parents of children with a disability are often very busy – ask for help if you need it so you have some time for all your children.
- Brothers and sisters can all have fun together and enjoy each other with support.
- Help the siblings work out how to explain the disability to their friends.
- It is important to give your other children permission to ask questions openly and to give them answers so they understand what is happening. Explain how the disability was caused, because children may worry about it happening to them, or feel they cause the problem in some way.
- Listen to children's feelings. Try and find some special time for each child in the family.
- All children need time to be children. Helping to care for a brother or sister can be good for children but they also need plenty of time to play and be with their own friends.
- Allow siblings to be involved eg: help choose the clothes for their brother or sister.
- Encourage brothers and sisters to be proud of their sibling's achievements and to realise the difficulties she may have had in getting there. Let them know that you are proud of their achievements as well.
- Make sure that the child with the disability does not destroy or damage other children's work or belongings. Give them a safe place to keep them if this is an issue.
- Remember that the other children need to be able to live their own lives and that plans for the future of the child with a disability should be made so that the other children do not feel there is a burden placed on them.

*What one sister of a young adult with a disability said, "I love my sister dearly and I would not wish things to be any other way. If she was "normal" then she would no longer be the sister that I love and know."*

## A Thought...

**Blessed are you that never bids us "hurry up" and more blessed are you that do not snatch our tasks from our hands to do them for us, for often we need time rather than help.**

**Blessed are you who take time to listen to defective speech, for you help us to know that if we persevere, we can be understood.**

**Blessed are you who walk with us in public places and ignore the stares of strangers, for in your companionship we find havens of relaxation.**

**Blessed are you who stand beside us as we enter new ventures, for our failures will be outweighed by times we surprise ourselves and you.**

**Blessed are you who ask for our help, for our greatest need is to be needed.**

**Blessed are you when by all these things you assure us that the thing that makes us individuals is not our peculiar muscles, nor our wounded nervous system, but is the God-given self that no infirmity can confine.**

**Blessed are those who realise that I am human and don't expect me to be saintly just because I am disabled.**

**Blessed are those who pick things up without being asked.**

**Blessed are those who understand that sometimes I am weak and not just lazy.**

**Blessed are those who forget my disability of the body and see the shape of my soul.**

**Blessed are those who see me as a whole person, unique and complete, and not as a "half" and one of God's mistakes.**

**Blessed are those who love me just as I am without wondering what I might have been like.**

**Blessed are my friends on whom I depend, for they are the substance and joy of my life!!!!**

by April Wells April 7, 1998 reprinted from Autism Resources

<http://www.unc.edu/~cory/autism-info/>

## ***The Neurobiology of Infantile Autism***

**by Roland D. Ciaranello, M.D.**

Infantile autism is one of the most disabling illnesses of neurologic, emotional and intellectual development. It afflicts about one in every 2,000 children, which makes it as common as cystic fibrosis or fragile X-mental retardation. Boys make up about 75 percent of all autistic individuals. In the San Francisco Bay Area alone, there are nearly 3,000 autistic persons. About 80 percent of autistic children develop signs of the disorder in the first year of life. By three years, the full-blown syndrome is usually present. Autistic children are generally normal in appearance, healthy and attractive; their life expectancy is normal.

The typical signs of autism include: withdrawal, isolation and aloofness; failure to develop language; preoccupation with inanimate objects, such as a spinning top or a light switch; ritualistic behaviours, such as endlessly arranging toys or objects by size, colour or shape; repetitive behaviours performed without interruption for extended periods of time, such as hand-flapping or flicking the fingers in front of the eyes; and an intense aversion to the slightest change, so that even the most trivial disruption of an established routine can cause extreme anxiety and emotional turmoil.

There is now quite convincing evidence that genetically regulated disturbances in brain development underlie some, perhaps most, of the cases of infantile autism. In 1971, Michael Rutter and his colleagues showed that autism occurred 50 to 150 times more frequently in families where there was already an autistic member. In monozygotic twins, when one is autistic, the other is also autistic more than 90 percent of the time. Estimates of the heritability of autism derived from both family and twin studies have ranged from 80 to 100 percent. Taken together, these studies provide substantive evidence that a genetic defect in brain development underlies infantile autism.

The human brain is an extraordinarily complex organ, made up of many different structures, each serving a distinct function. The development of the various parts of the brain is regulated by the complex interplay of genetics and environment. One of the most pressing questions scientists have been trying to answer is what part or parts of the brain are damaged in autism? The

areas which appear to be prime candidates are the structures of the limbic system and the cerebellum.

The limbic system consists of several different structures. We think the limbic system acts as both an augmentation and a switching centre, relaying information between brain areas while simultaneously adding emotional coloration to it. In monkeys, destruction of the amygdala, a part of the limbic system, causes a series of behaviours that closely resemble those of autistic children. Another part of the limbic system, the hippocampus, is known to be involved in the acquisition of recent memory.

Recent autopsy studies from Margaret Bauman and Thomas Kemper's laboratory at Harvard have shown that in both the hippocampus and amygdala there are nerve cells which appear to be immature and which have not migrated to their proper destination in the brains of autistic individuals. This suggests that there may be a defect in the normal developmental migration of these neurones, so that they do not reach their proper destinations, and so cannot establish their normal functions.

"These same investigators have also shown that there is a selective loss of Purkinje cells in the cerebellum of autistic individuals. This results in a loss of the neurones which make synaptic contacts with the Purkinje cells, ultimately involving many centres in the cerebellum. The significance of this observation is not clear, because the cerebellum's principal role is to aid in coordination of motor function and the position of the limbs and body in space.

"However, we know that the cerebellum receives extensive connections from the limbic structures and itself sends connections to the cerebral cortex, the major cognitive and information-processing centre for the brain. So it is possible that a defect in Purkinje cell development could impede the function of the cerebellum in ways we do not now understand.

What are the implications of all this for infantile autism? We now believe that autism represents a severe developmental disturbance of the brain that most likely occurs at the late or end stages of brain development, during which the final connections between brain cells are established that will define the communication network of the mature brain. We believe that these developmental disturbances giving rise to infantile autism are the result of genetic mutations, occur during the end

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stages of brain differentiation, and take place in circuits affecting the limbic structures, the temporal cortex and possibly the cerebellum that are responsible for language and information processing, and the emotional coloration that accompanies it. Like any hypothesis, this one must be verified experimentally.

These recent advances in an anatomic understanding of autism have also tied it more closely to another severe developmental disorder, schizophrenia. Schizophrenia is also a disorder of brain development which affects children and adolescents. There are two peak periods of risk for schizophrenia: one occurring about age 7 to 9 years, the second, larger peak, around 19 to 21 years. Schizophrenia is more common than autism, affecting around 1 percent of the population. Like autism, schizophrenia is a highly heritable disorder.

"For many years, researchers believed autism and schizophrenia were different variants of the same disorder, but epidemiological research showed that the two disorders did not occur more frequently in the same families than would be predicted by chance, so since about 1971, we have taught that they are distinct. However, more recent research suggests they may be related. Work from Patricia Goldman-Rakic's laboratory at Yale, Daniel Weinberger's laboratory at the National Institute of Mental Health, and Edward Jones' laboratory at the University of California, Irvine all implicates mal-development of centres in the medial temporal cortex and limbic structures in the pathogenesis of schizophrenia.

Moreover, at the cellular level, there is evidence that nerve cells do not mature properly in schizophrenics and that they may also not migrate properly. Thus there appear to be many common threads linking schizophrenia and autism. My own view, at this point unsupported by anything more than informed hunch, is different genes are responsible for schizophrenia and autism (thus explaining why they do not excessively co-occur in families) but that the biochemical function of these genes are highly related, and they may even be members of the same gene family. As more progress is made identifying the genes involved in autism and schizophrenia, we will have the opportunity to examine this hypothesis directly.

*Adapted from an article of the same name in The Journal. Reprinted from Autism Resources  
<http://www.unc.edu/~cory/autism-info/>*

## Current Interventions in Autism - A Brief Analysis

Polly A. Yarnall, M.Ed. *Advocate, Autism Society of America; Nov - Dec 2000; pg 26, 27*

*This chart is a simplified explanation and comparison of approaches currently in common practice. A more detailed review is available from the author.*

### Background

**Lovaas** also known as Discrete Trial (DT), Intensive Behaviour Intervention (IBI), Applied Behaviour Analysis (ABA); DT was earliest form of behaviour modification; initial research reported in 1987; initial intent to achieve inclusive kindergarten readiness; has "morphed" into IBI and ABA.

**TEACCH** stands for Treatment and Education of Autistic and related Communication- handicapped Children; over 32 years empirical data on efficacy of TEACCH approach exists; includes parents as co-therapists; recognises need for supports from early childhood through adulthood; main focus is on autism rather than behaviour.

**PECS** stands for Picture Exchange Communication System; derived from need to differentiate between talking and communicating; combines in-depth knowledge of speech therapy with understanding of communication where student does not typically attach meaning to words and lack of understanding of communication exists; high compatibility with TEACCH.

**Greenspan** also known as "Floor Time"; DIR (Developmental Individual-Difference Relationship-Based) Model; targets emotional development following developmental model; depends on informed and acute observations of child to determine current level of functioning; has child-centred focus; builds from the child "Floor Time" is only one piece of a three-part model that also includes spontaneity along with semi-structured play, and motor and sensory play.

**Inclusion** initially intended for children with mental retardation and disabilities other than autism; sociological, educational, and political mandates in contrast to psychology as root source for other approaches; inclusion defined in three federal laws - PL 94-142, REI, and IDEA.

**Social Stories** also known as Social Scripts; developed by Carol Gray in 1991 initially to help a student with autism understand rules of a game; was further developed to address understanding subtle social rules of "neurotypical" culture; addresses "Theory of Mind" deficits (the ability to take the perspective of another person).

### Goals

**Lovaas** teach child how to learn by focusing on developing skills in attending, imitation, receptive/ expres-

sive language, pre-academics, and self-help.

**TEACCH** provide strategies that support person throughout lifespan; facilitate autonomy at all levels of functioning; can be accommodated to individual needs.

**PECS** help child spontaneously initiate communicative interaction; help child understand the function of communication; develop communicative competency.

**Greenspan** targets personal interactions to facilitate mastery of developmental skills; helps professionals see child as functionally integrated and connected; does not treat in separate pieces for speech development, motor development, etc.

**Inclusion** educate children with disabilities with NT children to the maximum extent possible; educate children with disabilities in the chronological setting they would be in if they had no disability and they lived at home; does not apply separate educational channels except under specific circumstances.

**Social Stories** clarify social expectations for students with ASD; address issues from the student's perspective; redefine social misinterpretations; provide a guide for conduct or self-management in specific social situations.

## How Implemented

**Lovaas** uses ABC model; every trial or task given to the child consists of: antecedent - a directive or request for child to perform an action, behaviour - a response from the child that may include successful performance, non-compliance, no response, consequence - a reaction from the therapist, including a range of responses from strong positive reinforcement to faint praise to a negative "No!", pause - to separate trials from one another (inter-trial interval).

**TEACCH** clearly organised, structured, modified environments and activities; emphasis on visual learning modalities; uses functional contexts for teaching concepts; curriculum is individualised based on individual assessment; uses structure and predictability to promote spontaneous communication.

**PECS** recognises that young children with autism are not strongly influenced by social rewards; training begins with functional acts that bring child into contact with rewards; begins with physically assisted exchanges and proceeds through a hierarchy of eight phases; requires initial ratio of 2:1.

**Greenspan** teaches in interactive contexts; addresses developmental delays in sensory modulation motor planning and sequencing, and perceptual processing; usually done in 20-minute segments followed by 20-minute breaks, each segment addressing one each of above-identified delays.

**Inclusion** children with autism typically placed in inclusive settings with 1:1 aide; curriculum modified to accommodate specific learning strengths and deficits; re-

quires team approach to planning; approach may be selective inclusion (by subject matter or class), partial inclusion (½ day included, ½ day separate instruction), or full, radical inclusion with no exceptions.

**Social Stories** stories or scripts are specific to the person, addressing situations which are problematic for that individual; Social Stories typically comprised of three types of sentences: perspective, descriptive, and directive; types of sentences follow a ratio for frequency of inclusion in the Social Story; Social Story can be read TO or BY the person with autism; introduced far enough in advance of situation to allow multiple readings, but especially just before the situation is to occur.

## Reported Outcomes

**Lovaas** first replications of initial research reporting gains in IQ, language comprehension and expression, adaptive and social skills.

**TEACCH** gains in function and development; improved adaptation and increase in functional skills; learned skills generalized to other environments; North Carolina reports lowest parental stress rates and rate of requests for out-of-home placement, and highest successful employment rates.

**PECS** Pyramid Educational Consultants report incoming empirical data supporting: increased communicative competency among users (children understanding the function of communication); increasing reports of emerging spontaneous speech.

**Greenspan** teaches parents how to engage child in happier, more relaxed ways; hypothetically lays stronger framework for future neurological/ cognitive development.

**Inclusion** in certain circumstances, some children with autism can survive and even become more social in classrooms with NT peers; benefits children who cognitively match classmates.

**Social Stories** stabilisation of behaviour specific to the situation being addressed; reduction in frustration and anxiety of students; improved behaviour when approach is consistently implemented.

## Advantages of Approach

**Lovaas** recognises need for 1:1 instruction; utilises repetitions of learned responses until firmly embedded; tends to keep child engaged for increasing periods of time; effective at eliciting verbal production in select children; is a "jump start" for many children, with best outcomes for those in mild-to-moderate range.

**TEACCH** dynamic model that takes advantage of and incorporates research from multiple fields; model does not remain static; anticipates and supports inclusive strategies; compatible with PECS, Floor Time, OT, PT, selected therapies; addresses sub-types of autism, using individualised assessment and approach; identi-

ties emerging skills, with highest probability of success; modifiable to reduce stress on child and/or family.

**PECS** helps to get language started; addresses both the communicative and social deficits of autism; well-suited for pre-verbal and non-verbal children AND children with a higher Performance IQ than Verbal IQ; semantics of PECS more like spoken language than signing.

**Greenspan** addresses emotional development in contrast to other approaches, which tend to focus on cognitive development; avoids that which feeds child's deficit areas, drilling frustrations and highlights inadequacies; is a non-threatening approach; helps to turn child's actions into interactions.

**Inclusion** more opportunities for role modelling and social interaction; greater exposure to verbal communication; opportunities for peers to gain greater understanding tolerance for differences; greater opportunities for friendships with typically developing peers.

**Social Stories** developed specifically to address autistic social deficits; tailored to individual and specific needs; is time and cost efficient/flexible.

### Concerns with Approach

**Lovaas** heavily promoted as THE approach for autism in absence of any comparative research to support claim; no differentiation for subtypes when creating curriculum; emphasises compliance training, prompt dependence; heavy focus on behavioural approach may ignore underlying neurological aspects of autism, including issues of executive function and attention switching; may overstress child and/or family; costs reported as high as \$50,000 per child per year; prohibits equal access.

**TEACCH** belief that TEACCH "gives in" to autism rather than fighting it; seen by some as an exclusionary approach that segregates children with autism; does not place enough emphasis on communication and social development; independent work centres may isolate when there is a need to be with other children to develop social skills.

**PECS** may suppress spoken language (evidence is to the contrary).

**Greenspan** does not focus on specific areas for competency; no research to support efficacy for children with autism; approach based on hypotheses, not, research; is a more passive approach.

**Inclusion** automatic inclusion violates spirit and letter of IDEA; opportunities for successful inclusion begin to plateau by end of third grade as work becomes more abstract and faster paced; increasing use of language-based instruction puts students with autism at great disadvantage; sensory and processing difficulties tend to be insufficiently accommodated; regular education setting not necessarily best learning environment for students with autism; teachers and students in inclusion classrooms are typically ill prepared to receive student.

**Social Stories** supportive data is anecdotal rather than empirical; benefit depends on skill of writer and writer's understanding of autism, as well as writer's ability to take an autistic perspective.

### Errors to Avoid

**Lovaas** creating dependency on 1:1; overstressing child or family interpreting all behaviours as wilful rather than neurological manifestations of syndrome; ignoring sensory issues or processing difficulties; failing to recognise when it is time to move to another approach.

**TEACCH** failing to offer sufficient training, consultancy, and follow-up training to teachers for program to be properly implemented; treating TEACCH as a single classroom approach rather than a comprehensive continuum of supports and strategies; expecting minimally trained teacher to inform and train all other personnel in TEACCH approach; failing work collaboratively with parents.

**PECS** failing to strictly adhere to the teaching principals in Phase I; tendency to rush through Phase I or to use only one trainer; providing inadequate support or follow-up for teacher after attending two-day training; training only one person in approach rather than all classroom personnel; inconsistently implementing in classroom.

**Greenspan** attempting to implement approach without training or professional oversight; taking the lead, trying to get the child to do what YOU think he should do; allowing inadequate time; attempting to implement in midst of ongoing activities for other children.

**Inclusion** providing insufficient training, preparation, information, and support to personnel; placing student in settings where level of auditory and visual stimulation is typically too intense; assigning student work in which cognitive demands exceed student's ability to comprehend; depending on support of 1:1 aide; maintaining placement in face of frequent or severe disruptive behaviours; focusing on academics to detriment or exclusion of functional competencies; not offering multiple opportunities to apply functional skills.

**Social Stories** including too many directive sentences in proportion to perspective and descriptive sentences; stating directive sentences in inflexible terms (eg., "I will do" rather than "I will try to"); writing above the person's cognitive developmental age; using complex language; not being specific enough in describing either the situation or the desired behavioural response.

Reprinted from Autism Resources  
<http://www.unc.edu/~cory/autism-info/>

# BOOK REVIEW

## NEW ITEMS FOR THE AUTISM TASMANIA LIBRARY.

We are often asked about books which are suitable for siblings and we have recently purchased "Sibling of Children with Autism" which comes highly recommended. Also on our list is "Martian in the Playground", a book about understanding the schoolchild with Asperger's Syndrome. Rose Clark

- 1. **Siblings of Children with Autism – A Guide for Families**, Sandra L. Harris, Ph. D. Published by Woodbine Press, 1994.

This book is an invaluable guide to understanding sibling relationships, how autism affects these relationships, and what families can do to support their other children as they cope with the intensive needs of a child with autism. The author, Sandra Harris, offers compassionate and authoritative advice and strategies for dealing with specific issues that are often troublesome for siblings. She also teaches parents how to improve communication in the family, balance personal and family time, and foster interaction between children with autism and their brothers and sisters.

- 1. **Martians in the Playground – understanding the schoolchild with Asperger's Syndrome** by

Claire Sainsbury. Published by Lucky Duck Publishing Ltd, 2001.

Martian in the Playground is a new book which was the winner of the Best Academic Book Award National Association for Special Educational Needs Times Educational Supplement, November 2000. Author Claire Sainsbury has Asperger' Syndrome and has qualifications in Philosophy and Politics from New College, Oxford. She now works part-time with children and teens with autism, doing one-to-one work on basic communication and interaction skills. She also runs a website and e-mail support group for university students with Asperger's Syndrome and high-

functioning autism. The book covers: Asperger's Syndrome and the goals of education, a section on the classroom and the learning environment as well as the playground as a social environment. Aspects of the sensory and motor environment dealing with situations such as waiting in the lunch queue have a chapter devoted to them as do: secondary conditions and challenging behaviours, preparing for life after school and talking about Asperger's Syndrome.

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### Available from Autism Tasmania

**Autism Tasmania Information Kit**

\$12.00 includes postage for Parents

\$17.00 includes postage for Professionals

**Alert Cards \$2.00 for 12**

**Gold Lapel Pins \$3.00 + \$1.50pp**

**Asperger's Information booklet \$5.00incl pp**

## CENTALINK

Most parents of children with Autism receive the Child Disability Allowance.

Once their child reaches 16 years, he or she becomes eligible for a Disability pension

Arranging the transition from the allowance to the pension with Centalink does not seem to be a simple matter for some families.

Autism News invites members to write about their experiences with Centalink. If we find that members have had similar difficulties, Autism Tas may be able to lobby for changes on behalf of our members.

Cheryl Scott (Secretary)

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**WE WANT TO KNOW WHAT YOU THINK OF THE NEWSLETTER**

- \* Do you like the format?
- \* Do you enjoy the articles included in our newsletters?
- \* Would you like the newsletter to have a different cover page?
- \* Should each newsletter concentrate on a core topic as well as including the regular items such as book reviews etc.?
- \*What types of articles would you like to see in the newsletter that are not already included?

WE WOULD WELCOME ANY INPUT YOU HAVE TO THESE QUESTIONS AND ANY OTHER SUGGESTIONS – IF YOU HAVE EXAMPLES WHICH WOULD BE HELPFUL PLEASE INCLUDE THOSE TOO.

Send your thoughts to Cheryl Scott at her email address or c/o PO Box 1552, Launceston.