



AUTISM NEWS

Newsletter of Autism Tasmania Inc.

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From the Editor

In this issue, you will find a great deal of information about upcoming events. At the seminar held in March focusing on Autism Spectrum Disorders, once again there were numerous questions on diet and toileting, do these difficulties ever go away? Following on from the visit of Lawrie Bartak, Marg. Smith and Di Tribe we have invited Ms Vicki Colgrave to visit at the end of June as part of the Commonwealth Respite for Carers Program. Vicki is Dual Co-ordinator of the Early Intervention Centre at Irabina, and will be of particular interest to parents of young children and professionals working in this area.

On a different note over the past few months we have been discussing the direction that Autism Tasmania is taking. In the past twelve months we have seen the establishment of a centre for children with autism, the employment of an Autism Consultant by the Tasmanian Department of Education and community awareness of autism raised quite considerably, the result of several years work. We are presently planning a forum whereby your input is sought to plan the future direction of Autism Tasmania. Further information will be sent to you as the forum moves beyond the planning stage.

The Annual General Meeting is also coming up as are several support activities. A group of members in Hobart are meeting on a monthly basis - I'm sure you will all gain much from these get togethers as you support one another. Please feel free to join them. Northern members (all parents, but we do welcome others), had a very pleasant evening out recently at a local pub and have a couple of interesting evenings planned over the next few months. Unfortunately support activities in the North West are in decline, please contact Rose or Lis if you can assist here in any way. The value of parents particularly meeting and talking with other parents and learning from each others

experiences should never be underestimated.

From a personal point of view, I am planning to stand down as secretary at the Annual General Meeting. After four years the time has come to have a break and let someone else have a go. I am also conscious of the fact that I am now finding it difficult to carry out this role and meet the needs of my family. I look forward to handing the position over to someone with time, energy and a commitment to the growth of autism services in Tasmania.

Ros Ward -Secretary

Membership Renewal

Enclosed in this mailing is your opportunity to renew your membership for the next financial year. If you are wondering what the benefits of membership are, the following may give you an idea.

- * Four issues of Autism News - information on Autism and the activities of Autism Tasmania.
- * Access to information through seminars, conferences, and a gradually developing library of books and resources.
- * An opportunity for you to support the aims of Autism Tasmania.

Your membership is important to us. Please return your renewal as soon as possible.

What's Happening Near You!

We invite you to attend any of the activities listed below and hope you will take the opportunity to meet with others who have an interest in autism. While most of our support activities are organised with families in mind, and in particular parents, everyone is most welcome. Please come along and help to make these enjoyable occasions. **Mark them on your calendar or in your diary now!!!!!!**

HOBART:

Discussion evening: Thursday June 20th

To be held at the home of Rosemary Rush
48 Drysdale Avenue, Kingston at 8pm
Please bring a plate of nibbles.

Informal discussion evenings are currently being held on a monthly basis. If you are unable to attend this meeting, please contact Dulcie on (002) 448294 for details of July and August meetings.

NORTH WEST COAST:

After some sparsely attended social functions we have decided to put these **on hold**. Whilst Lis and I enjoy each others company it would be wonderful to have others to talk to. We were the only attendees at the Christmas Picnic and the recent video night! We would welcome your input and suggestions and would be delighted if you would like to organise a function. Please contact us on 24 3686 (Lis) or 23 1086 (Rose) - Rose Clark.

LAUNCESTON:

Discussion evening: Tuesday July 2nd

To be held at Ros and Mark Ward's
3 Grand View Place, Norwood, at 8pm.

Come along and meet Mrs Jenny Vince, Autism Consultant with the Tasmanian Education Department.

Casserole Evening: Saturday August 3rd

At the home of Yvonne and Neil Hawkins
4 William Street, Perth at 7.30pm

This should be a great evening. To assist with catering please bring a casserole to share and give Yvonne a call on 98 2919 or Ros on 43 2308 if you are able to attend. It helps if we know numbers!

Eating and Toileting Behaviours in Children with an Autism Spectrum Disorder

a seminar with

Ms Vicki Colgrave

South: Saturday 29 June at Timsbury Road School, Glenorchy

or

North: Sunday 30 June at Devonport Community Health Centre, Devonport

Ms Vicki Colgrave is a specialist Early Childhood teacher who has completed further studies and is currently a teacher and co-ordinator with the Irabina Early Intervention Program. She has considerable experience with young children, both through her role as a teacher and also as a respite carer. For further information and registration details contact Rose Clark (004) 23 1086 or Jenny Vince (002) 735 139

A Focus on Autism Spectrum Disorders

Approximately 140 people attended the seminar in March which focused on several aspects of Autism Spectrum Disorders. We have received a great deal of feedback regarding this day and welcome your comments.

We have recently received copies of the overheads used by Marg. Smith and Di Tribe. Contact Autism Tasmania if you would like copies of these.

Annual General Meeting

The annual general meeting of Autism Tasmania will be held in Launceston on Saturday 17th August. Further information will be forwarded to you as this date draws closer, including a call for nominations for committee members. Have you wondered what this involves?

Autism Tasmania committee meetings are held approximately every two months in Launceston, enabling state wide representation. Our broad agenda includes providing support activities; working towards improved services, including education and housing, for all people with autism (we are only just tipping the iceberg of this one!); publicity, information and the development of a library service; fundraising activities and the administration of the association. The list could probably go on but at present this is the agenda we have set ourselves.

If you would like to know more prior to the AGM, please feel free to contact a member of the committee.

Fundraising News

Autism Tasmania has this year engaged the services of Desmond Fletcher and Associates, Consultants to the non-profit sector. Desmond has prepared a submission seeking funding from a variety of sources for Autism Tasmania.

We have taken this step in an attempt to make Autism Tasmania a more professional body. At

present the only government funding received is tied to specific project, eg NEPS funding or Commonwealth Respite for Carers projects. While it is acknowledged that fundraising is essential in any organisation and we are not adverse to this, we would like to see Autism Tasmania develop. It may be community needs dictate that Autism Tasmania become a service provider and although our voluntary efforts have been significant they are at present inadequate to meet this need. We must be looking to secure the future of people with autism!

Toothbrush Drive

Thank you to those members and friends who supported the toothbrush drive. We raised over \$350.00 from this activity and were pleased with this amount.

Sock it to you is back!!!! Enclosed with this newsletter is an order form for this fundraising activity. Many of you have ordered socks in the past and again we hope you will take the opportunity to buy Australian made wool socks. (They are certainly some of the warmest socks I have ever had - Ed)

Please return orders by the end of June to:

Mrs E. Marshall
60 William Street
Devonport Tas 7310

Raffle - We are currently organising a raffle to hopefully be drawn during autism week in September. We would be grateful if members could take a book of tickets to sell; should you **not** wish to do so, please contact Lis Marshall on (004) 24 3686 otherwise a book will automatically be sent to all members.

Button Day - We have approval to have a button day to coincide with Autism Week and are seeking assistance from anyone who could help sell buttons throughout the state on Friday September 13th. Please contact Lis Marshall on (004) 24 3686 or Ros Ward on (003) 43 2308 if you are able to help in any way.

Feature Articles

PARENTS TALK WITH TEMPLE GRANDIN

Introduction: Temple Grandin is a high-functioning adult with autism, and is the author of the book "Emergence: Labelled Autistic "

The following were questions submitted to Temple by parents:

Q. What are the most effective early intervention programs for children with autism?

A. Any early intervention program that has the following ingredients are effective:-

1. One-on-one interaction with the child, which includes therapy (especially a speech pathologist). Keep the child busy for most of the day with at least two 45 min. sessions/day of physical exercise in addition to cognitive activities. Allow some "down" time - one half hour of TV/day is plenty, if it is being used for "stimming".

2. Sensory integration - If you can't afford to pay a therapist, do it yourself at home! Include exercises that provide deep pressure (such as squeezing the child between two mattresses) as well as games with steady motion such as a slow swing ride (10-12 times/minute). Keep swinging a game - never force vestibular motion as you can induce sensory overload or seizure. Signs of sensory overload will be the shutdown of hearing, vision or other senses. Since information can be processed best while these children are in motion, try combining this with a cognitive activity for maximum results.

A good program does not need to be expensive! Just go in and "jerk them out". You can get "The Me Book" which is all about the Lovaas Method and do it at home. "Let Me Hear your Voice" is the biography of a family who used the Lovaas Method to bring two of their children out of autism.

Q. What are the causes of autism?

A. 1. Immature development of the brain in the foetus.

2. Genetic - You will often see allergies, intellectual giftedness, eczema, left-handedness, visual thinking, anxiety disorder, depression, etc. in families with an autistic child.

3. Toxin/viral damage.

Q. Temple's opinion of auditory training?

A. It is useful in 50% of autistics. It helps with sound sensitivity and is good for kids with receptive language difficulties and hearing sensitivities.

For those who have had auditory training and find it wearing off a bit, don't rush back to re-do treatment. That should only happen if it wears off a lot. Re-doing it too soon could cause more problems. Don't do auditory training if you don't need it.

Q. Have you done any research on allergies?

A. The most common allergies are to milk, wheat, and gluten/grain.

Q. Are drugs useful with young children?

A. They should not be used for anxiety. But for seizures, yes. There is an exception for non-seizure autistics. Let's say you have done six months of very intensive intervention with no results and you have tried the B6/magnesium. Then try an anticonvulsant such as Depakote, Felbamate or Nevrontin and try it for about a month, using a high enough dosage to get a WOW reaction. If you don't see dramatic improvements, stop using it. This suggestion might bring back speech that was lost.

Work hard in the first seven years of the child's life while the brain still has plasticity.

Q. What kind of testing should be done on a newly diagnosed autistic child?

A. Check the thyroid - is it over or under-active? Sometimes P.K.U. is confused with autism.

Check for fragile X - it can be treated in much the same way as autism.

Check vision and hearing.

Try to do testing that will lead to some tangible treatment. Doing an M.R.I. only shows gross anatomy

of the brain and if something is wrong, you can't do a brain transplant.

Q. What are signs of seizures?

A. Staring spells often are a sign of small seizures. Brain immaturity can be manifested in laughing and screaming in rapid succession.

Q. What are the best ways to teach autistic children?

A. Types like Temple who are on the left side of the spectrum (Kanner/ Asperger type, often high-functioning) respond best to being "jerked" out of their autism. Temple's mother and speech therapist grabbed her chin and made her repeat words.

Types like Donna Williams who are on the opposite end of the spectrum (regressive/epileptic type) will have sensory overload if they are pushed too far. They often can use only one channel at a time, such as sight or hearing. Be gentle with these ones. Sing, speak softly and don't force eye contact. Talk slowly as their brain works slowly. Do cognitive learning while engaged in a physical activity such as balancing on a moving stool. For some reason, this vestibular activity stabilises the sensory process and calms the child so they can concentrate better.

Encourage echolalia! It is the beginning of speech, so don't shut it off.

Q. How do you teach gentleness with other children?

A. Work on touch sensitivity. Gradually work on tolerating gentle touch, then increase it. Don't force touch on them or they will shut down. The brain needs regular tactile input to grow and develop.

Q. Should we allow our child to play a full game of Nintendo (even if it takes him one and a half hours to finish)?

A. If you are sure he is not using it to self-stimulate it's okay, but try to find another activity that is more physically involved to substitute where possible.

Q. Is it possible that a vaccination reaction can trigger autism?

A. Some autistic children may have been predisposed to autism anyway and the shots brought it on. It could be an allergic reaction to the vaccine. It is difficult to isolate the exact cause as the brain is going through a

developmental change between 18 months - 2 years, just when vaccinations are given.

Autopsy research shows that abnormalities in the brain cells happen during foetal life.

Q. How do we teach visual learners?

A. Visual thinkers have a CD Rom memory. They store memories like a computer and tend to think from specific to general in their memories. They have no generic memory as "normal" brains do (i.e. Temple remembers a specific church steeple. Normal brains automatically see a generic type in their mind's eye).

Her thoughts are based entirely on what she sees. So avoid long strings of verbal information, which is hard to process. Give as much written instructions as possible.

Q. Are there side effects to vitamin therapy?

A. There is a slight possibility of nerve damage if B6 is taken alone. In combination with magnesium and in the NuThera compound that is endorsed by Dr. Rimland of the Autism Research Institute, there is very little chance of nerve damage happening.

Q. Would Temple recommend anxiety drugs for children younger than 13?

A. Temple's anxiety started at puberty. She got all the classic anxiety disorder symptoms. For some autistics the symptoms can come earlier. Anxiety worsens with age generally. So if you do give anti-anxiety drugs before puberty, make sure they have a real WOW effect.

Half of autistic adults need drugs for nerves, such as Clonidine (for blood pressure) and Beta blockers.

Q. How can you explain autism to a child so he will feel good about himself?

A. If he is going to make it in school, he has to realise he is different. Tell him out and out what is expected such as cleanliness, social cues, etc... but make concessions with touch sensitivity (type of clothing he can tolerate). For example, videotape the child and have him learn how to correct his own errors by watching and being coached. Teach him rote rules of conduct.

Q. How does Temple control frustrations and anger for herself when she reaches a stressful level?

A. She avoids confrontation — she doesn't allow herself to get mad. Also, she will cry.

Q. How can you build self-esteem in autistic children?

A. Find something they do very well and build on it. Use their fixations to develop a meaningful activity.

13 years to adult

Q. What role do drugs have in treating autism?

A. 50% of autistic adults need some form of medication to decrease anxiety. Anxiety levels increase as the population grows older.

Anti-depressants excite one set of nerves as they calm another set of nerves. Be careful of wrong dosages which can cause serious trouble. Find a dosage that works and stick with it, even through the relapses, as anxiety can be cyclical.

For epileptics, stick to serotonin receptable inhibitors. Don't ever touch tricyclics.

Anxiety may also be treated with blood pressure medications (Beta blockers) such as Clonidine.

Avoid Valium which is most useful for subduing people who are over the edge, or to give pain relief. It is not for anxiety. Prozac may benefit aggressive adults.

Sudden outbursts of anger may really be indicating a seizure disorder, which may not have shown up on an EEG. EEG's only record what happens during the testing process.

Take people off a drug slowly, so as not to induce a seizure. Changes should be seen over a short period of time to make the drug worthwhile. If that doesn't happen, try something else.

Q. How can we compensate for sensory difficulties?

A. If an autistic individual is tactile defensive, provide him with soft clothing. Reconsider changing clothes from season to season (Temple's standard fare is jeans and a shirt).

If light bothers their eyes, consider tinted glasses. In the States you can get "Blue Blockers" which are very close to the colours Helen Irlen discovered to work the best for visual distortions. "Blue Blockers" are a lot cheaper than Irlen lenses! Greens and yellows don't work.

Shades of brown, grey or pink work.

If hearing is super-sensitive, get auditory training for the individual.

Q. How did Temple deal with her own sexuality? What was her awareness?

A. It has never been of interest to Temple. She is celibate. Some autistic individuals are aware of their sexuality, but are often taken advantage of because they don't understand all the hidden meanings. If two autistic people marry, they have a 1 in 3 chance of having an autistic child.

Q. Is there any comparison between schizophrenia and autism?

A. No, they are totally different. Autistics don't hallucinate. Autistics get scrambled sensory intake which is often confused with schizophrenic behaviours. Autism is early onset. An autistic person doesn't believe they are Henry VIII! Hearing and visual sensitivities can vary widely amongst the autistic population.

Q. How does Temple cope with social situations?

A. She avoids social interaction. She has difficulty reading people's expressions. Her teen years were very difficult. It is good if autistics can make their friends through special gifts or interests they have. Steer teens into areas of talent and really develop them. Finding a mentor for an autistic teen is very important.

Temple gets her satisfaction not through social relationships, but through tangible results as a result of her lecturing and working with parents of autistic individuals. You will find her at home on New Year's Eve answering letters, drawing a new design or watching TV!

Temple stressed that autistics have to live with high levels of anxiety.

They do not have complex emotions. The primary emotion is often fear and perseverations are driven often by anxiety.

Reprinted from Keynotes, Published by the Autistic Association of NSW, Issue 1, March 1996. For further information contact the AANSW Librarian.

HELPING THE CHILD WITH AUTISM TO UNDERSTANDING TRANSITIONS

by Laura Grofer

Reprinted from the Autistic Association of New South Wales, March 1995 in "Information Regarding Suitability of School Resource Kit. Originally published and reprinted with permission from The Advocate, Vol 21., No.4., January 1990.

By making transitions predictable, we will help children to understand their environments and realise that they do have some control over their lives.

Children with autism have difficulty processing information that is novel and unpredictable. They prefer to interact with people and objects in a stable, predictable environment. For these children, changes or transitions are unknown, uncontrollable events that happen to them. Viewed in this way, it is easy to understand why children with autism tend to become confused and upset during transitions.

Fortunately there are several simple techniques teachers and parents can use to make transitions as predictable and understandable as possible for children with autism. Although the following examples focus on strategies used by teachers, these same suggestions can be adapted by parents to use at home.

There are several ways in which transitions between activities and environments can be simplified for children with autism. First it is important for teachers and parents to give children plenty of warning before any type of transition occurs. This will give the child with autism time to prepare for a change. For example in school the teacher may want to tell the class when an activity is about to end and a new activity is about to begin.

Since children with autism often fail to comprehend instructions given to the class in general, teachers may want to tell each child individually about the impending transition.

For some children having a timer or watch on their desks may clarify the boundaries of when one activity ends and another begins. For children who need this amount of structure it is important that transitions occur at the expected time.

Written schedules are useful in helping to establish predictable routines for children with autism. There are many different types of schedules that can be developed

depending upon the child's cognitive abilities.

For a child with limited language and reading skills, it may be helpful to use a daily schedule with photographs of the child engaging in different activities. Prior to each transition the child can put away the picture of the previous activity.

For children who can read and tell time, a list of the day's activities along with the times that they occur may help make transitions predictable.

The use of daily schedules allows teachers flexibility in their programming as long as the changes are announced at the beginning of the day when the schedule is initially presented to the child.

Additionally giving the child an object that represents the future may even help the future to become more understandable. Therefore during transitions it is often helpful to give the child with autism a transitional object to carry from one activity to the next. For example if the next activity is gym, the child can carry a ball.

Since changes are often viewed as uncontrollable events it is important for children to learn that they have some control over their environments.

Allow the child with autism to make choices about transitions. For example if the next activity is reading, allow the child to choose what book to read or the person that will listen to the child's reading.

Ideally if children with autism are allowed to make choices they will begin to initiate activities rather than waiting to be told what to do.

...there are several simple techniques teachers and parents can use to make transitions as predictable and understandable as possible.

Transitions between environments can be simplified if there is good communication between the two environments. Using a journal between home and school helps parents and teachers to respond consistently to particular behaviours.

If a child learns one thing at school and the opposite at home the transition between home and school will be a difficult one. Additionally a journal will help parents and teachers understand what happened in the previous environment. For example if an unexpected fire alarm happened at school, it will be helpful for parents to know that this upsetting event occurred.

In addition to learning that transitions can be controllable and predictable, it is important for children with autism to learn to generalise information across transitions.

Often children with autism will learn to perform a task in one specific environment with one specific set of cues. For example a child with autism may learn to read the word "walk" on a picture card in the classroom, but not understand when the word "walk" is flashing from a sign.

Ideally children with autism should be taught in the naturalistic environment in which they will actually use the behaviour. This often necessitates teaching children with autism in the community. So in the above example the child would learn the meaning of the word "walk" while standing at a street corner reading the sign.

Since some concepts are applicable to many different situations, it is useful to expose the child with autism to a variety of these situations. For example if the child is learning to understand the word "roll" it may be helpful to demonstrate that a person can roll, a ball can roll, a truck can roll, etc. this teaching strategy can be used to reach many different concepts.

All of these suggestions can be adapted to each individual with autism. With a little creativity we can make transitions more predictable for children with autism. By making transitions predictable we will help children to understand their environments and realise that they do have some control over their lives.

HINTS FOR HELPING A DISTRACTIBLE CHILD PROCESS AND IMPLEMENT INSTRUCTIONS

The following list of suggestions is made to assist parents with a child who is easily distracted, has difficulty paying attention, and has difficulty remembering what he/she has been asked to do.

1. Before issuing instructions, be sure to gain the child's attention.
2. Don't try to call instructions from another room, or when competing noise may prevent the child from hearing.
3. Keep instructions short and simple.
4. Check that the message has been received by getting the child to tell it back to you. This step helps two-way communication by giving feedback, and also aids memory through repetition of the instruction.
5. Speak softly and firmly and stay calm. **DO NOT YELL.**
6. Be prepared to repeat instructions calmly.
7. Reward correct compliance.
8. Keep a sense of humour.
9. Establish routines so that instruction giving is minimised.
10. For complicated instructions, write a note that the child can refer back to.

*Adapted by Anthony Warren, 1995
Metropolitan Outreach Service
Autistic Association of New South Wales
Reprinted from Keynotes, Issue 1, March
1996.*

NEWS AND VIEWS

Disability and Education

The area of disability and education continues to be a controversial issue. Ms Anita Smith, Disability Discrimination Legal Advocate (Nth), has received complaints from parents of children with varied disabilities who have had poor experiences with the Special Education system in Tasmania. She is preparing a submission, calling for a review of the system and the operation of the Inclusion policy to date.

Autism Tasmania acknowledges that at present there are difficulties with the allocation of funding to children with an autism spectrum disorder. Regular meetings have taken place with Ms Kerry Channell, Manager State Support Service and Jenny Vince, Autism Consultant, to discuss the general issues affecting children with autism. The department recognise that determining "a cut off point" for funding within Autism Spectrum Disorders is problematic and have been looking closely at the Victorian situation as a result. Many of the issues and concerns are in fact the same in both states.

Within Tasmania, the DECCD (formerly DEA) is planning to initiate a new record of students diagnosed with Autism Spectrum Disorders. This will include students with mild through to severe autism and Asperger syndrome (not PDDNOS). This database will be separate from the Category A register and will clearly recognise and identify students with autism. The database may assist to identify students who require support from their district support service in addition to those students who may also be on the Category A register.

We will keep you informed of developments within this area, but DECCD is genuinely attempting to acknowledge and address the needs of students with autism in the most fair and equitable way within the constraints of available resources. Autism Tasmania will continue to liaise with DECCD regarding this very important issue.

Book Review by Rose Clark

"The World of the Autistic Child." Understanding and Treating Autistic Spectrum Disorders.

Written by Bryna Siegal. Oxford University press. 1996. Currently available as a hardcover selling for approximately \$42.95.

This is a very detailed book on Autism Spectrum Disorders, written by an American author, Dr Bryna Siegal who is a developmental psychologist and director of a large university clinic for autistic children. The book is comprehensive and was written for the parents of autistic children, for their teachers, child specialists and other professionals who care for them.

Dr Siegal believes that a parents best defence is to acquire as early as possible the knowledge and the parenting skills they will need to work with professionals to help their child reach his or her full potential.

Personally the book is the most comprehensive I have read on the subject of Autism Spectrum Disorders. It is straightforward and sympathetic dealing with the myriad of symptoms and labels, obtaining a diagnosis, explaining the crucial importance of intensive early education along with discussing behaviour modification, the acquisition of daily living skills through to the role of traditional academics in educating higher functioning children. There is also an interesting section where Asperger syndrome is contrasted with autism.

It is so thorough it's difficult to explain briefly. It is well worth looking through (as some of our recent interstate guests found) and is available in Tasmania. (I bought my copy in Burnie).

Study - Stress in Families

Last year Rose Clark participated in a study RMIT (Royal Melbourne Institute of Technology) was conducting into sleep problems in children with autism. The results of this study are currently being collated and will be released soon. The sleep study was done by a Master of Psychology student and was supervised by Dr Amanda Richdale.

This year another Masters student is doing a study on stresses experienced by families who have a child diagnosed as having autism, Asperger syndrome, Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS) or Down syndrome.

If you are interested in participating contact Rose on (004) 23 1086 as Dr Richdale (Supervisor) and Kylie Burke (Student) have sent her multiple copies of their letter which explains how you can participate. They are hoping that many Tasmanian families will be involved in this study.

Disability Consumer Forums

Disability Consumer Forums are being held in Launceston on a regular basis. The forums give people with disabilities, their families and carers the chance to meet and discuss issues which are important to their well being.

The main aim of the Disability Forum is to give people the choice to be involved in decisions made about the services they need and how those services are provided. The forums are planned to help people have their needs heard by management and those who plan services.

Paula Barnes has attended a number of forums and encourages others to join her, particularly parents of adolescents and adults with autism. On the last occasion, two forums were held, both during the day and in the evening to enable as many people as possible to attend. Contact Paula on (003) 97 3379 for further information regarding northern forums or Disability Services in the south and north west.

Autism Week Activities September 8-15th 1996



Plans for Autism Week are well underway. In the south there will be a BBQ on Sunday September 8th to launch the weeks activities. The BBQ will be held at Gumbles Adventure Park, Richmond and will get underway at 11.00am. The park has car, train and merry go-round rides and cost is \$5.00 per child, adults are free.

In the north a family day will be held on Sunday September 15th. We will begin at the Miniature Railway in Ulverstone followed by a BBQ and activities at the Playhouse in Devonport. There will be a wonderful face painter in attendance for the children who will paint faces, hands or arms. More information will be available prior to Autism Week.

As mentioned earlier in the newsletter, we will be selling buttons around the state on Friday September 13th. We desperately need people who can help with this activity even if only for an hour or so.

Other happenings are in the pipeline too, including updating our community services announcements for television and media releases. Wendy Kennedy from Tasmania Today is keen to do an interview regarding autism.

We need your help!!!!

On Saturday 15th June, we have booked a table at the Orana "Great Expectations" Day on the North West Coast. Committee members will be attending a meeting on this day and will be unable to "man" the information table. If you can help between 10am and 3pm we would be pleased to hear from you. Contact Rose on 23 1086 ASAP.

Sibling Support: An Overview

Deborah Perrott was a Family Counsellor with Autism Victoria last year. This article is based on a presentation Deborah made discussing issues for siblings. A full copy of this paper, including references, is available from AUTISM VICTORIA. The article is reprinted from Autism News, Published by Autism Victoria, December, 1995.

Over the past twelve months a growing proportion of my role as Family Counsellor has been providing support and education to siblings where there is a child with Autism or Asperger Syndrome. Working with siblings is not only a challenging task, but also highlights to me the great need for work to be undertaken in this area. Many siblings have a number of issues that have never been addressed before. Often misconceptions about their brother or sister or themselves are resolved by simply explaining the disorder and possible cause(s). Behavioural problems with the child with Autism/Asperger are most often discussed and strategies can be provided to siblings to help cope with various situations. This is not only empowering and positive for the sibling, but also, in many cases a relief. Siblings also appreciate knowing there are others in their same situation. Siblings are provided with ongoing support and are free to use the phone counselling service on a needs basis. The following is a summary of the literature and research in the area of siblings.

Research Summary

There is limited research in the area of siblings of children with autism and other Pervasive Developmental Disorders. Previous research has considered the effects of autism on the family.

In relation to how siblings of children with autism compare to other siblings, there is little research. It appears that there are both positive and negative effects on siblings. There is much controversy amongst researchers regarding difficulties of adaptation of siblings. Some believe that being the sibling of a child with autism results in adjustment difficulties, others suggest that there is no degree of difficulty. We must recognise that siblings of "normal" children can at any time experience social and psychological stressors including changes in family roles, change of home structure, loss of parental attention, negative emotional thoughts and experiences - the list is endless. As

McHale et al (1986) point out, it is difficult to know whether emotions of siblings such as jealousy and rivalry with children with a disability are any different from that which exists between non-disabled children. Also, there is limited research in the area of "normal" sibling development to compare findings with.

Research has included factors such as the relationship between the severity of the disability and sibling adjustment. There have however been no studies conducted relating specifically to autism.

Gender of sibling studies indicate that brothers and sisters play different roles within the context of the family and in relating to the child with autism. For example, sisters will often take an active caretaking role; brothers do not. Factors such as this cannot be considered in isolation, as mothers of disabled children reported that pre-school sisters hold more responsibility for child care and household tasks than pre-school brothers and more than siblings in the control group. McHale and Pawletko (1992) found that siblings of disabled children spent more time on chores than disabled children and siblings of non-disabled children. Although research findings indicate that siblings do spend more time on household tasks, Mates (1990) suggests that this increased responsibility does not necessarily lead to poor performance in achievements and behaviour at school and at home.

Related to the birth order of siblings, Mates (1990) included the oldest sibling of a family with a child with autism and found no differences between brothers and sisters on self concept measures and home or school behaviour adjustments. McHale et al (1986) found that on one questionnaire item presented, younger siblings expressed more negative feelings toward the child with autism, than older siblings.

Research on family size indicates that larger family size was associated with less embarrassment about the sibling as rated by mothers, and fewer feelings of burden as reported by siblings.

Related to psychological factors, Gold (1993) researched

depression and social adjustments in siblings of boys with autism compared to other siblings. Results indicated that siblings (brothers) with autism scored higher on depression than the comparison group, but not on problems of social adjustment. It should be noted that there were higher numbers of adolescent boys in the autistic sibling group compared to the comparison group which may have effected the results. Perceived competence and behavioural adjustments of siblings with children with autism indicated that although siblings had more internalising and externalising behaviour problems when compared to other siblings, results fell within the normal range. (Rodrigue, Geffkon and Morgan, 1993). This suggests that "the siblings of a child with autism are not necessarily susceptible to poor psychological functioning". As Lobato (1983) suggests, there is a complex relationship between various factors. These in turn can produce either positive or negative influences effecting individual sibling performance.

Potential Positive Effects (Lobato, 1990) These include maturity, responsibility, altruism, tolerance, humanitarian concerns and careers, sense of closeness in the family and self confidence and independence .

Potential Negative Effects (Lobato, 1990) These include feelings of parental neglect, feelings of resentment, perceived parental demands and expectations for achievement, embarrassment, guilt about their own health, extra responsibility at home, restrictions on social activity and sense of distance in the family.

Each sibling is unique in personality, past experiences and daily needs. Depending upon the age of the sibling and their circumstances, Lobato (1990) compiled a list of common needs expressed by siblings of disabled children:

- (1) Information on the child's condition including how it is evaluated and treated.
- (2) Open communication with the family about the problem and family members positive and negative experiences with it.
- (3) Recognition by parents of the siblings own strength and accomplishments.
- (4) Need for "quality time" with parents on an individual basis.
- (5) Contact and support from other siblings and families.
- (6) Ways to cope with stressful events such as peer and public reaction, unexpected disruptions to family plans and extra home responsibility.

There are a number of unique concerns relating to young siblings that Lobato (1983) draws our attention to:

- * Confusion about the child's developmental or medical problems.
- * Misconceptions of the cause of the problem.
- * Emotional distress among parents and other family members.
- * Disruptions in plans and family routines.
- * Prolonged and frequent absence of the child and parents.
- * Frequent medical and therapy appointments.
- * Heightened attention to the child.
- * Comparisons of health and development.

Further research is indicated to evaluate the positive and negative long term effects of the sibling(s). Also, research is required to investigate the effect that services for individuals with autism impacts on the sibling relationship. For example, early intervention programmes and respite care.

It is vital that both parents and professionals are aware of the specific needs of siblings. These needs must be addressed appropriately and effectively. Carers and workers need to understand how to firstly acknowledge siblings needs and secondly how to address them. It is important that those working with the sibling(s) know how to obtain professional support, advice and information.

A Ten-Step Practical Approach to Sibling Support/Education

The rate at which this process is worked through, is very much dependent upon the child's needs, age, number of issues presented and number of siblings present.

- (1) Establish rapport with sibling(s).
- (2) Respect the siblings need to be seen and heard as an individual.
- (3) Understand the siblings concerns related to:
 - the sibling with autism
 - schooling issues
 - social issues
 - role of sibling in the family
 - level of knowledge of disability
- (4) Allow sibling to prioritise needs and decide what to work on.
- (5) Allow sibling to identify with other siblings through literature.
- (6) Education regarding autism.
- (7) Identify with the sibling with autism.
- (8) Coping strategies for various behaviours.
- (9) Exploring the positives of the sibling with autism.
- (10) Provide ongoing support - allow child to contact you on a regular or needs basis.

Giant Steps Update

The first full years operation at Giant Steps has been completed. The children are making steady progress much to the delight of their families. Interested parents and professionals continue to visit the centre to learn more about the program including Marg. Smith and Di Tribe who spent a day at the centre while in Tasmania in March. The young staff at Giant Steps enjoyed the opportunity to exchange ideas with professionals experienced in working with children with autism.

It has been a difficult year in many respects. The Board of Directors has been working to consolidate the long term financial viability of the program, seeking assistance from Michael Downes of Downes, Venn and Associates, a firm of fundraising consultants. Michael conducted a feasibility study into the fundraising potential of Giant Steps Tasmania and believed that in order to operate confidently in the future, Giant Steps would need approximately 80% of the required funding for operational costs to be covered by government, either State or Federal or a combination of both.

The State Government has made a three year funding commitment, but the amount involved is insufficient to cover the running costs of this labour intensive program. Giant Steps was able to take advantage of the Federal New Works Opportunities Programme in 1995, and the Jobskills Programme this year, but these will come to an end in August. To ensure that Giant Steps can confidently and properly operate in the long term, the Board of Directors has been seeking to secure additional long term recurrent funding from governments.

A meeting between State and Federal Health and Education Departments as well as representatives from Giant Steps was held in May to look at the long term funding options. In what Giant Steps hopes is the beginning of an ongoing process, all possible avenues of funding are being pursued.

Even if Giant Steps is able to secure a substantial contribution from State and Federal Governments, the remaining required funds need to be raised

through private sources. Parents of children attending the centre pay fees comparable to other private schools in Tasmania, despite the fact that this requires an enormous sacrifice from many families.

A particular initiative from the Board of Directors has been the instigation of the "Sponsor a Child" project. Individuals or organisations are able to sponsor a child for \$240.00 per year and in return they receive a package with a photo and information about one of the children. Lions Clubs throughout the state have adopted this project.

There have been a number of recent staff changes at the centre. Teacher Jo Kilby has moved on to work with visually impaired children and her position has been taken up by Jane Phillips from the Deloraine area. Jane has experience in working with special needs children. Gillian Miller, who came to Giant Steps on a twelve month secondment as the Occupational Therapist, has recently returned to Queensland. Her position has been taken by Jane Shrimpton from Victoria. Sherelle Dye, Program Co-ordinator, recently tendered her resignation and the Board has advertised her position both internally and externally.

Several staff took the opportunity to visit Montreal during the January break, mostly at their own expense. Holiday training for shadows through formal therapy assistant traineeships will begin during the June holidays.

It was inevitable there would be teething problems in establishing a new program and it has been an extremely stressful year for the staff. Giant Steps will miss the experience and expertise of those staff members who have chosen to leave.

Rachel Evans has replaced Rose Clark as a nominee of Autism Tasmania on the Board of Directors. Rachel is a speech pathologist with the DECCD. We owe a vote of thanks to Rose who was also a member of the original Giant Steps steering committee.

Autism Tasmania Library

Until such time as we have an official "base" Lis Marshall is operating the library from her home. You are welcome to contact her to borrow books or videos or obtain copies of articles. The following is a list of some of the resources we currently have.

Books

Attwood, Tony	Why does Chris do that?
Autism Association of SA	The Student with autism/Asperger syndrome in the school community
Baron-Cohen, Simon	Autism: The facts
Curtis, Joan	A Family Affair
Mereno, Susan	High functioning individuals with autism
Williams, Donna	Nobody Nowhere
Williams, Donna	Somebody Somewhere

Videos

AFSA (Vic)	Autism, The Early Signs
Autistic Association of SA	What is autism?
Proceedings	National Autism Conference, Melbourne 1992

Audio Tapes

Attwood, Tony	Family Seminar - Hobart 1993
Proceedings	National Autism Conference, Brisbane 1995
L. Bartak, D Tribe and M. Smith	A Focus on Autism Spectrum Disorders, Launceston 1996

Articles

Attwood, Tony	Asperger Syndrome - identification in schools
	Three types of autistic child
	Why do repetitive actions occur?
	Do autistic children have unique learning problems?
	The Australian scale of Asperger syndrome
Autistic Association of NSW	Hints which may help at home

	Tips for surviving the holidays
Bartak, Lawrence	Briefing notes on autism and Asperger syndrome
	What's an autistic spectrum disorder and what's in a name?
Bettison, Sue	Abnormal responses to sound and the long term effects of a new treatment program
	Auditory integration training
Bitsika, Vicki	Identification and treatment of children with autism
Carruthers, Anne	Asperger syndrome: a brief overview
Clark, Alison	On being a mother of an autistic child
Giant Steps Tasmania	General Information
Hayward, Barbara	Siblings of children with autism
Hoffman, Wendy	Autism: diagnosis, assessment and management
Kershaw, Leonie	Assisting individuals with autism to anticipate routines and changes in routines through the use of augmentative communication systems
	Putting parents in the picture: running communication workshops for parents
Newson, Elizabeth	Enabling flexibility and social empathy in able autistic children
	Evaluating interventions in autism: problems and results
	Supporting parents as members of the team for the autistic child

Newsletters

Autistic Association of NSW	Keynotes (quarterly)
Autism Victoria	Autism News (quarterly)
Autistic Chn's Association of QLD	Autism Queensland (quarterly)
Autism Association of ACT	Autism Awareness (quarterly)
ARRI	Newsletter of Autism Research Institute, US (quarterly)
National Autistic Society	Communication, UK (quarterly)