

# ***AUTISM NEWS***

Newsletter of Autism Tasmania Inc.

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## *Autism Tasmania Committee*

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Rachel Evans (004) 31 9273 (work)

**Secretary** Ros Ward (003) 43 2308

**Treasurer** Ron Barnes (003) 43 1293

**Committee Members** Elisabeth Marshall (004) 24 3686

Michael Freeman (004) 42 2039

Paula Barnes (003) 43 1293

Jenny Vince (002) 73 5139 (work)

Dulcie Montgomerie (002) 44 8294

### ***Annual General Meeting***

The third annual general meeting of Autism Tasmania was held recently in Hobart. Thank you to those people who attended and in particular Jenny Vince who was our guest speaker. Jenny gave an account of her position as autism consultant with the DEA and a report on her talk is included in the issue.

As you can see the committee has undergone a few changes. We farewell Michael and Elizabeth Rutledge who have stood down from their positions. Michael has been Treasurer since the formation of Autism Tasmania and given a great deal of his time to the organisation. Elizabeth has been Vice President for the past twelve months, but has been actively involved as a contact point for autism in Hobart over the past three years. Elizabeth and Michael did an outstanding job with the organisation of our first "Attwood on Autism" seminar which did a great deal to lift awareness of autism in Tasmania. We thank them for their participation and contribution to Autism Tasmania and wish them and their family, Ryan, Alison and Patrick all the best.

For the first time in our short history we had an election for office bearers. There were three nominations for the position of Vice President; Rose Clark, Rachel Evans and Michael Freeman. Rose and Rachel were elected to these positions. Michael was re-elected to the committee along with Lis Marshall. We welcome our newest committee members, Paula Barnes, Jenny Vince, Dulcie Montgomerie and Ron Barnes to the position of Treasurer. Paula and Ron have become increasingly involved over the last few months in the north and are keen to continue and develop the work already begun. Their son, Michael was recently diagnosed with high functioning autism at the age of 24!

Prior to the AGM no nominations from the south had been received. As the constitution requires the committee to be made up of at least two representatives

from each region, nominations from the south were called for on the day. We look forward to working closely with Jenny to further develop services for all people with autism. Last but not least, we welcome Dulcie Montgomerie to the committee. Dulcie is the grandmother of a young boy diagnosed with PDDNOS and is keen to assist wherever possible.

A copy of the annual report will be forwarded to you in the near future.

### ***From the Editor***

Again my apologies for the delay in getting this issue of Autism News to print. I had hoped to have it out before the end of term, but a major computer breakdown put a stop to that. Fortunately Mark managed to retrieve most of this issue but several pages had to be rewritten.

Like the rest of the committee I am committed to Autism Tasmania and its growth but as a volunteer there is a limit to the amount of time I can give on some days. Maybe one day we will have some paid administrative support to assist with the functions of our association!

It has been an exciting few months. We have seen the appointment of Jenny Vince to the temporary position of Autism Consultant with the Department of Education, and in June we saw the opening of the Giant Steps centre at Deloraine. These events are the beginning of autism **specific** services in our state.

Please note closely our family activities for National Autism Week and look for our television announcements again this year. Everyone is welcome to attend our family days; parents, children, extended families and any interested professionals. Hope to see you there!

Ros Ward  
Secretary

Official Launch  
by  
The Minister for Health, The Hon. Roger Groom

The official launch of National Autism Week will take place on Sunday 10th September. We invite you to join us at either of the following events.

Devonport - Ulverston

Commencing at the Miniature Railway in Ulverston, address.... from 10.30am till 11.30am. We will then move to The Playhouse in Devonport for a Sausage Sizzle and Family Day. The Minister will formally launch Autism week in Tasmania around 12.30pm.

Hobart

A family BBQ will be held at Wentworth Park in Howrah.

National Autism Week 1995

*10th-16th September*

National Autism Week is once again nearly here and a range of activities is being organised. The Minister for Health, Hon. Roger Groom has accepted our invitation to launch Autism Week and this will occur in Devonport on Sunday 10th September. The flier sent out last week gave full details of this day. A family day is also being held in Hobart and we hope you will be able to join us at one of these functions.

We have once again organised to show community announcements on television. Ray Martin is happy for us to use the "commercial" he produced for us last year and this will be aired on WINTV. Southern Cross will also play their announcement - the two are slightly different - for two weeks beginning on Sunday 10th.

A poster competition has been conducted amongst some schools on "The Face of Autism". Schools

that have children with autism attending were invited to participate with Jenny Vince's co-operation. Posters were received from New Norfolk and Roseneath Schools. The winning entries were from Sonia Riley, Grade 2/3 at New Norfolk and Nicole Robbins, also grade 2/3 at Roseneath. The girls will be awarded with a Gift Voucher for their schools by Jenny. All other children who competed will be awarded with a merit certificate.

The posters will be displayed during Autism Week at Claremont Village in Hobart. Autism displays will also be held in Launceston and Devonport. If you can assist by "manning" a stall at all, contact a committee member in your region.

A street stall and display will also be conducted by the Friends of Giant Steps (FROGS) in Deloraine on Saturday 16th September.

# **Major Raffle**

*First Prize: Rinnai Kombi Gas BBQ with trolley, sponsored by \$500.00  
The Gas Corporation of Tasmania*

*Second Prize: LOUGHRANS Open Order, sponsored by Loughrans \$250.00*

*Third Prize: Large overnight bag with matching belt bag \$50.00  
sponsored by Mrs E. Marshall*

*Fourth Prize: Cross-stitched towel set sponsored by Mrs J. Jones \$35.00*

*Fifth Prize: Handmade Teddy sponsored by Mrs C. Van Zelm \$20.00*

Autism Tasmania is running the above raffle with tickets now available. Tickets are in books of ten and are selling for \$1 per ticket. We would be most grateful if you could take some books to buy or sell. Please contact any of the committee and we will organise to forward books to you. The raffle will be drawn at an Autism Tasmania function on the 24th November 1995 at Cafe de Collins, in Devonport. All prizes have been sponsored or donated and we particularly thank the Gas Corporation and Loughrans for their support.

**Phone Autism Tasmania as soon as possible to obtain a book of tickets.**

## ***Northern Dates***

**Date:** Wednesday 27th September

**Where:** 3 Grand View Place  
Norwood

**For:** Coffee, Nibbles and a Chat

**Time:** 7.45pm

Phone Ros or Paula - all welcome

**Date:** Wednesday 18th October

**Where:** Walker House Family Health Centre  
17A Walkers Ave, Newnham

**For:** Discussion Evening - Respite Care  
Guest Speaker - Family Based Care

**Time:** 7.30pm

Phone Ros or Paula for further information

## ***North West Dates***

**Date:** Saturday 14th October

**Where:** Venue in Ulverstone - still to be decided

**Time:** 7.30pm

**For:** Dinner

RSVP to Rose - please ring to find out venue.

## ***Raffle Drawing***

The drawing of our raffle will occur on Saturday 24th November at the Cafe De Collins, William St, Devonport. Dinner will commence at 7.30pm and the raffle will be drawn during the evening. Contact Lis Marshall for further details.

## Regional Sub-Committees

*Are you interested in assisting with the organisation of various activities held in your region?*

At the AGM it was decided to enlarge the committee to 10 members with a minimum of two representatives from each region. We do not envisage growing beyond this but the extra numbers will give us slightly more flexibility. For a number of reasons we usually find that one or two people are unable to attend committee meetings.

In some regions we have members who are wanting to assist in some way but not be involved to the point where they need to travel to Launceston for meetings. As a result three co-ordinators will be appointed from the committee to develop sub-committees in each region. These will be appointed at our next committee meeting.

Your co-ordinator in your region will invite you to help if you wish to do so, by arranging sub committee meetings. These meetings will be an opportunity to plan activities, including social get togethers, meetings with guest speakers, or statewide activities that may be occurring in your area. This will assist committee members with the wide range of activities we find ourselves organising.

Please take the opportunity to be involved if you wish, but there is absolutely no pressure upon members to do so.

### *Respite for Carers*

In the 1994/95 financial year we received a grant under the Commonwealth Respite for Carers program to provide parents and carers with the opportunity to get together, while funding respite care for the children. This took the form of either care at the venue or private care. Workshops were led by guests from the mainland, Dr Lawrie Bartak, Ms Amanda Golding, Ms Vicki Bitsika, Ms Verity Botroff and Mr Mark Page.

We have been fortunate to gain recurrent funding to operate further functions which give parents creative respite. We are looking at holding a statewide function later this year, again providing you with respite care either at the venue or privately. Details of this function

are still being finalised, so look out for further information.

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### **AUTISM: ASSESSMENT, DIAGNOSIS AND MANAGEMENT.**

Wendy Hoffmann - TPTC BBSoc MPsych MAPsS  
Child Psychologist

Autism Tasmania recently received a copy of Wendy Hoffmann's completely revised paper "Autism, Assessment, Diagnosis and Management". Wendy is a child psychologist working in Melbourne.

The Victorian Interpreting and Translation service has translated the paper into the following languages for the VACAA.

Spanish Khmer (Cambodian) Greek  
Chinese Turkish Arabic  
Vietnamese Italian

The paper is available for purchase at a cost of \$2.00 for each language or \$10.00 for the set.

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## **1995/96 Membership Renewals**

Thank you to those members who have sent in their membership renewals. If you haven't received your receipt it is enclosed with this issue. Your continued support is appreciated by all at Autism Tasmania.

If according to our records your subscription is still outstanding, a coloured subs form has been enclosed with this issue. Please forward your payment as soon as possible if you wish to continue receiving your copy Autism News and information about the association.

### *New Logo*

At the AGM we decided to amend the logo slightly to keep in line with the National Association. We have adopted a new jigsaw piece without the hole in the head.

### **National Autism Association - AGM**

The AGM of the National Autism Association will be held in Canberra in September. Mark will be attending and it is hoped that by meeting in the National Capital, arrangements can be made to meet with specific politicians. We'll keep you informed of any outcomes.

# FEATURE ARTICLES

Reprinted with permission from Autism News  
Victorian Autistic Children's & Adults Association - June 1995.

In a previous edition of AUTISM NEWS, we printed an article about "Sensory Experience and Autism. In this issue, Ms Hilarie Kohn, an Occupational Therapist in Melbourne, discusses a therapy found to help a number of children with autism who appear to have heightened sensory experience.

In May this year Professor Bruce Tonge, Monash Medical Centre, held an information evening for parents - "Drug Therapies in Autism". A summary of his talk is printed for your information.

## SENSORY INTEGRATION AND AUTISM SPECTRUM DISORDERS

### WHAT IS SENSORY INTEGRATION?

Sensory integration is the process which occurs when our brain organises and interprets the information from our senses. The developing process of sensory integration usually occurs in childhood. For some children and adults with Autism Spectrum Disorders this has not been the case which results in difficulties in the way they relate to the world around them.

Our senses provide us with information about how our body is interacting with the world. When eating an orange we taste, see and smell the orange. We also receive information from our hands and mouth about the texture of the orange fruit, its skin, flesh and juice. Without thinking we know the position of our fingers and tongue and whether we are sitting, standing or moving while we eat.

Our brain organises and prioritises sensory information automatically.

When we focus on the taste of the orange, we are unaware of our body position. When the chair slips our focus shifts. The ability to alter our focus in this way relies on a well integrated sensory motor system which can receive, organise and interpret information for us to make a response. In this case if our sensory motor system is functioning in an integrated way we would automatically begin to adjust our body to stop us falling before we thought about what was happening.

### WHAT IS MOTOR PLANNING?

Picture a baby lying still in a cot with a mobile above him. As his mother lifts him he brushes against the mobile. His sense of touch is stimulated. The baby has received sensory input. He looks and swipes at the mobile. The baby swiping at the mobile is planning movement using the sensory information he has integrated from his eyes and body. This process is called motor planning and is

not automatic. It is dependent on the baby wanting to reach the mobile and planning a movement.

Initially it is through our experience of planned movement that we learn how to affect the outside world. Rather than just receiving sensory input we act on it and receive sensory information from our body about the movement we have made. This combined system is called a sensory motor system.

Our sense of touch (tactile system), sense of movement against gravity (vestibular system), and the position of our body (proprioception) give us a map of our body. They also tell us where we are in relation to the ground and what we are touching. Sometimes these three senses are called the body senses or the somatosensory system. The senses of taste, smell, sight and hearing tell us about the things around our body.

### THE THEORY OF SENSORY INTEGRATION AND AUTISM.

The concept of Sensory Integration Therapy was developed by A. Jean Ayers PhD OTR. In her theory, Dr Ayers was interested particularly in the integration of the body senses and their affect on the development of motor planning and learning in everyday life. The theory has continued to be developed and its application extended since its original description.

Sensory integration concerns the meaningful combination of sensory input, how it affects our level of alertness, our movements and the registration and modulation of sensory input.

The registration of input occurs when our nervous system notices some input, like the beginning of our fall from the chair. Modulation is our ability to receive input from our senses that is useful and then filter and balance it. If we noticed everything equally or by one sense only to the exclusion of all others the world would be a confusing

place.

There is an increasing interest in the sensory experiences of children and adults with autism. The descriptions of their own sensory experiences by adults who have autism has further promoted our interest in this area. Sensory integration theory or treatment does not claim to explain or be beneficial in all sensory difficulties. The approach can be useful when considering behaviour and planning to maximise development and learning opportunities.

The theory offers some insight into aspects of autism, but is not a comprehensive explanation for the varied and divergent sensory and motor problems seen in autism and related disorders.

WHAT CAN BE DONE .....

#### SENSORY INTEGRATION THERAPY.

Sensory Integration Therapy is an individual therapy based on the principles of Sensory Integration. It is conducted by an Occupational Therapist with specialist training. An initial assessment is completed to identify those areas of difficulty that may be assisted by this form of intervention. When possible a standardised assessment is completed. In addition structured observations, information provided by other professionals and input from parents are used to establish the goals of therapy.

Sensory Integration Therapy may be combined with other treatment techniques to maximise achievement of goals. It is one tool that an Occupational Therapist can use in combination with a number of other treatment techniques.

Sensory Integration Therapy is child centred and uses the child's initiative and motivation to direct therapy within the therapists aims. The aim is not to teach a skill such as jumping, but to develop the background so the child can run, hop, skip or jump more easily. Therapists use different sensory inputs to encourage the child to respond to the environment and to help their nervous systems to notice and then balance the sensations in a useful way.

The experience of being actively involved in an enjoyable activity pitched to their individual level of achievement helps the child to organise themselves in more mature patterns.

Sensory Integration Therapy can assist in reducing a sensory difficulty such as an overresponsiveness to touch. It can aide a child's gradual development towards increased motor skills. As a treatment approach with people with autism it is particularly important to note that the therapy is aimed at maximising the person's capacity and reducing their sensory difficulties over a period of

treatment. An effective approach is in combination with behavioural and environmental management strategies.

#### WHAT CAN BE DONE IN GENERAL?

The theory of Sensory Integration can help us to understand a person's behaviour. Using this approach we can see the behaviour of those with autism as related to their ability to respond and deal with sensory input from the environment.

Is the adult or child who enters the supermarket and careers off the shelves or hides in fear responding to an overly stimulating environment because he is unable to process the sensory information?

By looking closely at behaviour and the sensory input from the environment we may be able to help the person to cope by reducing the sensory demands or by providing an alternate environment which has a calming effect in combination with behavioural and other management strategies.

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\* In this article, the term "autism" has been used in place

of the longer term "Autism Spectrum Disorders".

EDITOR'S NOTES:

(1) I have occasionally been asked, is the Primary School Perceptual Motor Program the same as Sensory Integration Therapy? The answer is clearly no. PMP is a skill building program, and is derived from a different body of knowledge to that of Sensory Integration Therapy.

(2) Temple Grandin in *Emergence: Labelled Autistic* and other writings has spoken often about her sensory experiences. At one presentation she spoke to parents and passed on some suggestions and observations. (Taken from the Edmonton Autism Society Journal, Winter '95):

\* Some children have sensory oversensitivity while others have sensory jumbling and mixing... The child who has a lesser amount of sensory processing difficulties will be attracted to an item that arouses his senses. The child with the mega sensory processing trouble will be fearful of the item."

\* She suggests carpets and drapes to cut down on light and noise, bean bags and sleeping bags for security, and heavy coats when visiting events which could provide sensory overload.

\* Temple is in favour of Sensory Integration Therapy - "swings in the classroom to help the vestibular system."

\* "If tooth brushing is difficult, massage of gums and teeth with a finger can over time reduce the sensitivity to brushing teeth."

\* Eating problems may well have a sensory origin. For example, the child may refuse to eat crunchy foods because the noise chewing creates is intolerable, and so the child is aversive to the pain related to eating that type of food."

\* "Another therapy of use to ... people with autism is the use of exercise. I would suggest long hikes, running and swimming."

Thank you Hilarie for this valuable article. (Amanda Golding, Executive Officer, VACAA, Editor Autism News, Victoria )

*Reprinted from AUTISM RESEARCH REVIEW INTERNATIONAL, Volume 9, Number 2, 1995.*

# Medication and Autism

*The following article has been prepared from notes taken at a recent presentation given by professor Bruce Tonge, and an article published in The Advocate, Autism Society of America, Jan - Feb 1994, pages 27-29, entitled "Medication Issues in Autism".*

"Everyone who works or lives with a person who has autism knows that there is no medication which will cure autism. There is no medical intervention which can reverse or undo the underlying neurophysiological basis of the disorder. Educational... (and Behavioural Management) programming are the most important factors in improving the quality of life for a person with autism. However, self injury, aggressive behaviour, hyperactivity, seizures, depression, or extreme anxiety can interfere with a person with autism's ability to learn and cope with the world. Rational use of medications may be able to create a window in a challenging behaviour, may control seizures or anxiety, and can allow learning to take place.

Medications are not a substitute for an individual plan of positive behavioural supports for the person with autism. The plan should include environmental changes, positive programming, a communication system, direct, intervention by reinforcing a more appropriate behaviour which serves the same function, and a reactive plan." - The Advocate.

Professor Tonge referred at length to the criteria that should be met when considering use of medication (King, Ollendick & Tonge, 1993).

They are:

1. A comprehensive assessment leading to a diagnosis using an accepted classification system such as the DSM III-R or DSM IV or the ICD-10.
2. Identification of specific symptoms and behaviours that are known to be modified by medication therapy.
3. Consideration of these in the context of social, family, psychological, developmental and biological contributing factors.
4. An assessment that they are causing definite distress to the person and are of such severity that there is a definite impairment in social and mental functioning and school/work performance.

5. There is an indication that other behavioural type therapies have not been effective, or that these approaches are likely to be enhanced by the addition of drug therapy.

6. The selection of a single drug for the task which has the fewest side effects and the lowest possible toxicity.

7. Careful explanation to the parents, carers and possibly the person being treated as to the purpose, action and possible side effects of the drug prescribed. This includes careful explanation of the dosage regime.

8. Care that the family/carer has ready access to regular medical follow up for supervision of ongoing treatment via a monitoring of progress, check on side effects and supervision cessation of the medication when appropriate.

There are four groups of specific Psychotropic drugs, as well as the Anxiolytics and Sedatives, and a number of other drugs which can be considered for use by a child or older person with autism. (NB. The following comments relate specifically to their possible use for our particular client group. The comments are summary only, and are not exhaustive.

## **Mood Altering Drugs**

These are MAOI antidepressants and Cyclic antidepressants. The former are not used with children. In the latter group is Imipramine and Prozac, among others. They are used to treat depression, especially in teenagers, and anxiety, which can inhibit learning and social interactions. These drugs treat a feature of the person's autism, not the autism itself.

## **Mood Stabilising Drugs**

These include Lithium and anticonvulsants like

Tegretol, for depression and mood swings. These conditions can be very difficult to determine in autism, and items 3, 4 and 5 in the Criteria for Drug Use should be carefully appraised.

### **Neuroleptic Drugs**

Melleril and Haloperidol (Serenace) are being used for symptomatic treatment of stereotypic, self-stimulatory and self injurious behaviours. They can produce major side effects which are usually dose related. Careful monitoring of dosage is needed, and drug free holidays are often recommended.

### **Stimulant Medications**

Also known as amphetamines. The most known is Ritalin which can be beneficial for children with autism who have AD(H)D - Attention Deficit (Hyperactive) Disorder, by reducing their hyperactivity and improving concentration levels. It is not used for autistic behaviours alone.

### **Anxiolytics and Sedatives**

Known names are Mogadon and Valium. These have no role to play in medication for children. They can be addictive and do not help underlying issues. Their value may lie in short term use for extreme distress, but they can often have a paradoxical effect by hyping children up.

If poor sleeping is a significant issue, it may be better to use an antihistamine formulation such as Valergan or Phenergen to produce drowsiness. An observant physician could treat the anxiety around bedtime with an antidepressant.

### **Other drugs**

Tegretol can be used to control episodic outbursts of aggression where total loss of control occurs. This person may have an unstable EEG, and there could be fitting which is not immediately apparent.

Fenfluramine is an appetite suppressant, which acts on the brain by altering serotonin levels. Much more research is needed, but trials have shown some reductions in autistic symptoms, especially in the area of language and communication.

Clonidine is used for high blood pressure by controlling adrenalin flow. It may have an application in autism where there is evidence of higher adrenalin flow.

Beta adrenergic blockers such as Propranolol have some use in the treatment of aggression in intellectually disabled persons, as well as anxiety and panic disorders. They should not be used if the person has cardiorespiratory conditions such as asthma.

Opiate blockers are natural pain relievers. There is evidence that Naltrexone may assist in cases of severe self injurious behaviour, and produce improvements in communication - but much of this work is still experimental.

Finally, there are a number of vitamins and other "non-drug" substances whose supporters claim are successful. However, these claims are based on anecdotal evidence rather than solid research. It is of concern that there does not seem to be common agreement on dosage levels, nor are there controls on standard "formulations" of these substances.

In conclusion, "...medications are not the only answer to behaviour problems, but used along with a positive educational program and necessary environmental adaptations, they can sometimes help the individual with autism participate more fully. When parents, teachers, and physicians all work together, follow an agreed upon plan, and communicate honestly and factually with each other, medication use can be assessed individually for each person and the best quality of life achieved." The Advocate, page 29.

*If you have any queries about the medications noted above, the best person to ask is your paediatrician or psychiatrist - do not hesitate to ask if these professionals are experienced in treating behaviour problems. Use your gut feeling, and do not hesitate to get a second opinion.*

# NEWS AND VIEWS

## **AUTISM CONSULTANT**

The Department of Education and the Arts has appointed Mrs Jenny Vince to the temporary position of Autism Consultant. Jenny was guest speaker at our AGM and spoke of her role within the department. She was also happy to participate in a general discussion and answered many questions put to her. Jenny has a keen interest in autism and nominated for a position on the committee of Autism Tasmania in a bid to see all parties working together.

Jenny has a teaching background and as such is unable to diagnose autism. However, at the request of government schools she is available to be contacted as the first point of call for students. She will offer recommendations for further assessment if she feels this is required. Students will be referred to the children's assessment centres in Hobart, Launceston and Burnie where Jenny aims to develop multi disciplinary teams able to competently diagnose the disorder. Jenny has so far had contact with the assessment centres in Hobart and Burnie. She is very conscious of the fact that we need to build up the expertise on autism in Tasmania both in terms of assessment, diagnosis and management.

Jenny's other main role is to support classroom teachers who have students with autism in their classes and offer professional development. Individual Education Plans for students with autism are compiled in consultation with the classroom teacher. Unfortunately at this stage she is not able to give hands on support to families, although she has been assisting a few families in the north west where there seems to be a concentration of young children with autism.

What access do parents have to the Autism Consultant? Individuals can request assistance from Jenny (self-refer) and she can be contacted through Timsbury Road School in Glenorchy. She has on occasions visited parents at home before seeing the child at school. To date she has seen 59 children from schools all around the state. If you are unsure whether Jenny has seen your child you are keen to meet with her when she visit the school, talk with your child's teacher or give Jenny a call.

Jenny also spoke about funding for children with autism and the difference between Category A and Category B funding and who is eligible for what. Category A children are those with minor incidence disabilities which includes moderate to severe autism. Children with mild autism are considered for Category B status. The funding issue is extremely complex and as Category B funding is

determined at a district level there may be differences between districts on how funding is allocated.

Jenny was in Melbourne during the last week of the school term to spend time with Dr Lawrie Bartak and Dr Philip Graves as well as visiting Irabina and Mentone schools. She also spent time with Amanda Golding. The information she will have gained during this week will be invaluable. We were excited when Jenny nominated for the committee and look forward to working closely with her.

## **GIANT STEPS REPORT**

After nearly three years of intense work by a number of people, a Giant Steps centre was officially opened in Deloraine by the Premier of Tasmania, The Hon Ray Groom. The centre is a satellite of the Giant Steps centre in Montreal, Canada.

Fifteen children are enrolled at the centre, ranging in ages from three to eleven with varying degrees of severity of autism. The staff is headed by Program Co-ordinator, Sherelle Dye who also conducts some music therapy sessions and a multi-disciplinary team of professional staff, Teacher - Jo Kilby, Occupational Therapist - Gillian Miller, Speech Therapist - Arlene Lewis and Play and Communication specialist - Andrew Woodard. As well the staff comprises specialists in music, activities of daily living, computers, a team of dedicated shadows and ancillary staff. The staff work very much as a team with the children's needs paramount.

The day is split into four sessions and the children move between therapies with their shadows. All therapies are received at least once per week by each child. Although there have been teething problems (to be expected), the children have settled in well. An observation week was recently held, giving parents the opportunity to watch their children working in all areas.

A team of staff from Canada was in Tasmania for two weeks in June to assist with the beginning of the program. The staff then travelled to Sydney to open a second Australian satellite. Sydney parents became aware of the Giant Steps program after seeing a program on "A Current Affair" featuring the Triffitt family while they were in Kamloops. There is now interest in other states regarding this program.

It is an extremely intensive program and at present there is a 1-1 ratio of staff to children at the Tasmanian centre.

Fundraising activities have a major focus to supplement the government funding received. FROGS (Friends and Relatives of Giant Steps) has been formed not only to raise public awareness of Giant Steps but to assist with raising funds for the centre. FROGS meet in Deloraine approximately every second Wednesday and the next meeting will be held on the 20th September at 12noon upstairs in London House (Above the Amcal Pharmacy). All interested people are welcome to attend, contact Penny Cromarty on (003) 34 1119 for further information.

Applications continue to be received from both Tasmanian families and from interstate. When an application is received it must not only be considered by Giant Steps but be forwarded to the Tasmanian Department of Education for funding purposes. The child is considered by the Department for eligibility for Category A funding dependent upon having a diagnosis of Autism according to available assessment data. (DSM IV).

If you are interested in more information on Giant Steps you can contact the centre on (003) 622522.

## **Nobody Nowhere by Donna Williams**

*Although Nobody Nowhere was first published in 1992 and will be familiar to many of our members, it may not be known to those members who have recently joined Autism Tasmania. Donna has autism, and has written a further book titled Somebody Somewhere. Lis Marshall contributed the following article, her thoughts of Donna's book.*

I first read "Nobody Nowhere" very early in my quest for answers regarding my high functioning son. It was a scary experience. It was also a revelation.

Here too was somebody who had been thought of by other people and herself a combination of deaf, retarded, crazy, abnormal, weird and insane. In her quest to find answers about herself she writes an autobiography and about three quarters of the way through comes to the realisation she has autism. She showed her manuscript to a psychiatrist and it was confirmed.

My opinion is that Donna is a brave and resilient person. She had what seems to me a quite horrific childhood and early adulthood with not a great deal of family support and plenty of abuse. That she survived at all is a testament to her strength of character.

It is a book that not only has taught me a lot about my son, but also about myself. A compelling read that is hard to

put down. (I'll confess....I read it in one sitting and my family had to have take-a-ways for tea!!)

## **Eye-poking: link to calcium levels?**

Autistic children who hit or poke their eyes may respond to calcium supplementation, according to a preliminary report by Mary Coleman.

"Although ocular self-abuse is rare," Coleman says, "the four patients with autism seen in [our] Clinic who experienced this symptom were all found to have hypocalcemia [low urinary calcium levels]." Three of these patients reduced or stopped their self-injury when given calcium supplements. The fourth moved, and researchers were unable to follow his case.

Coleman describes one adult patient with hypocalcemia who actually removed one of his own eyes, and attempted to injure the other eye. Thirty-six hours after being placed on calcium supplements and anticonvulsants he stopped touching his good eye, and he has exhibited no ocular self-injury since then.

Coleman and colleagues reported two decades ago that 22% of autistic children they studied had urinary calcium levels more than two standard deviations below the mean. Similar results were seen in a 1985 study by D. Rosenthal. The findings are difficult to understand, Coleman says, since blood levels of calcium are normal in autistic children, as are parathyroid hormones (which mobilise calcium from bone when calcium levels are depressed).

Coleman notes that "there is a large literature on low levels of calcium in the central nervous system associated with seizures," and points out that calcium plays an important role in the biosynthesis of the neurotransmitters dopamine and serotonin.

"Clinical presentations of patients with autism and hypocalcemia," Mary Coleman, *Developmental Brain Dysfunction* 7, 1994, pp. 63-70. Address not listed.

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## **Disability Discrimination**

Paula Barnes

In Launceston recently I had the pleasure of attending an informal luncheon meeting with Disability Discrimination Commissioner, Elizabeth Hastings, followed by an open forum during which the Commissioner spoke about the Disability Discrimination Act.

The luncheon was modest....two plates of tired looking club sandwiches and self service plastic tea and coffee. In contrast, the Commissioners' address was filled with mouth watering disability discrimination delicacies, served with tempting anecdotes and examples with liberal helpings of humour. The luncheon and the Commissioners talk shared one thing in common, I left wanting more of each!

Commissioner Hastings began by saying that there is still no state government legislation in Tasmania to protect people against discrimination, unlike the other states and territories. People were disadvantaged, because without a local focus, they were less likely to be aware of the terms or provisions of such legislation and of the strength it gives those with disabilities negotiating every day things, such as access to goods and services, education, employment, public transport and so on.

The Commissioner said that we should no longer be content to regard a lack of accessibility to areas which others enjoy, as "Oh well! That's life!" and gave an example: "If you have a disability such as mine and use a wheelchair, you probably don't go to the pictures much. If you do go, it is something planned well in advance and you go with a friend. The choice of film is usually dictated by the accessibility of the cinema rather than film preference." Commissioner Hastings went on to say that this was discrimination. Even though no one has directly said, "... you can't come here. We don't like people with disabilities" the cinema itself says so - and that is indirect discrimination. The Commonwealth Disability Discrimination Act makes indirect discrimination equally as unlawful as direct discrimination.

Elizabeth Hastings then explained who was covered by the D.D.A. saying that it was an offence to discriminate on the basis of physical, psychiatric, intellectual, sensory, neurological and learning disability and that it is unlawful to discriminate

against that persons associate, carer, parent, spouse or partner.

Not surprisingly, there was some confusion amongst the audience between prejudicial attitudes and discrimination but the Commissioner was quick to correct any misapprehension by saying, "Discrimination has occurred if a person with a disability is treated unfairly or less favourably than another person without that disability. This can be direct discrimination, for example if an employer recognises that a person with a disability has the qualifications and abilities for a job but will not employ them because of the existence of the disability, perhaps through fear of damaging the company's "corporate image". Or the discrimination can be indirect, as I have already described.

The Commissioner said that it is unlawful to discriminate in nearly every aspect of community living. We were given numerous situations and various scenarios but of particular interest to me was her reference to education. With regards to education the Act makes it unlawful for education authorities to refuse application for admission by a student on the grounds of disability. Neither must they limit access to any benefit provided by that authority, nor expel a student or deny benefits accorded to others, unless there is a defence of unjustifiable hardship. Most complaints brought to the Commissioner concerned withdrawal or absence of assistance, for youngsters with disabilities to be educated in mainstream schools. Later, in a passionate exchange with a member of the forum, the Commissioner said that it was the right of every child, regardless of disability, to receive education and whilst it is always the prerogative of parents to choose to pay for private education, education should be available to all without the need to pay.

The Commissioner continued her vibrant speech by saying that a person, child or adult with a disability wants to "belong" and yet current jargon used in education circles (but not exclusively) implies quite the opposite. "Inclusion" for example, "Integration" and "Mainstreaming" are words which signify difference and places the power of decision, of action, firmly in the hands of those "including" "integrating" and "welcoming" committees. Such words as "inclusion" are still founded on the assumption that, there are children and then there are children with

disabilities!

She continued by saying that the Act requires schools, teachers, planners and policy makers develop non-discriminatory mainstream educational environments and that parents and students can begin to demand them. Some parents may prefer to send their children to schools the D.D.A. would now describe as "special measures" or indeed to private schools, but whatever your choice, all schools must now provide discrimination free education to those children with disabilities unless they can demonstrate unjustifiable hardship. Schools should enable all students access to all areas of the curriculum and to programs which include information about conception, pregnancy, childrearing and so forth, for these are essential to all children's education, to their sense of self and of worth, including those with disabilities. Commissioner Hastings added that many students with disabilities have been restricted in future choices because of the narrow curricula of "special" schools. Education was high on the Commissioners priority for the coming year.

The Commissioner's speech covered a whole range of issues and despite a gnawing in my stomach it was not sufficient to distract me from a stimulating and most informative afternoon. The forum also provided an excellent opportunity to meet and talk with other group representatives and government agency personnel.

I was rather pleased to meet with our northern Disability Discrimination Solicitor, Anita Smith, and delighted when she offered to talk with our northern Discussion/ Support group about the Act and its significance for us as a group and as individuals.

Anita addressed a small group of parents on a cold winters evening late in July when she was not feeling well. Disability Discrimination is a topical issue and her talk to Autism Tasmania was the third that day. Anita has left private practice to take up this work and she too is passionate about the rights of the disabled. She is keen to mediate rather than confront and she has advocated positively for people with disabilities.

Anita can be contacted on (003) 34 1577.

## **Name Changes**

Two Autism Associations have recently, or are about to change their name. The Autism Association of the ACT for Children, Adolescents and Adults Inc has become **Autism Association ACT Inc** and the Victorian Autistic Children's and Adults' Association (VACAA) will be launched as **Autism Victoria Inc** during National Autism Week. Both states have considerably shortened their names and removed the word autistic in favour of autism. It seems that Autism Tasmania made a good decision back in 1992 when selecting our name!!!!

## **New Leaflet**

Included with this issue of Autism News is a copy of our updated leaflet. We thank Windmill Educational Supplies for their support in producing this leaflet and Regal Press for their prompt service!!!

What do you think? If you can assist with distributing leaflets to child health clinics, community health centres or doctors surgeries etc, including paediatricians, please contact Autism Tasmania.

## **Thanks**

Our thanks to the following companies who have supported Autism Tasmania over the past year. Their support is appreciated.

Windmill Educational Supplies

Australian Paper

The Gas Corporation of Tasmania

Loughrans

Lactos, Arnotts, Roelf Vos, 4 Ways Cake Shop (Devonport), Golden Gumnut Bakery, Sams 4 Ways Supermarket (Devonport).

There are many people who assist us on an ongoing basis and we thank you for your efforts.