



# ***AUTISM NEWS***

**Newsletter of Autism Tasmania Inc.**

*Postal Address*

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## BRANCH BUSINESS

### FROM THE PRESIDENT

Our first issue for 2001 contains a wide variety of articles and information which make very interesting reading.

Each year issues relating to Autism Spectrum Disorder confront us. One that keeps recurring is that of Assessment and Diagnosis as many parents are confused about where to go for this important step in their child's life. In recent months, we have received many comments from parents who have had negative experiences during this somewhat difficult time. At the January meeting, the committee of Autism Tasmania decided to concentrate on this area by providing opportunities for Professional Development for those involved in the field of Assessment and Diagnosis.

To begin this process, Wendy Lawson is visiting the state in late April to speak with professionals about Diagnosis and related issues in both the North and South of the state.

Later in the year, there will be a training component in Assessment and Diagnosis during the National Biennial Autism Conference in Adelaide. Your committee is currently assessing how we can best access training for Tasmanian professionals, who may be interested in attending.

August this year will also see a visit by Carol Gray from the US. Carol publishes the very useful newsletter "The Morning News" which has many wonderful articles – particularly focussing on Bullying in the most recent. You will see an

extract in this newsletter. Carol has been at the forefront of the development of Social Stories, which have been very successfully used with people of all ages with Autism Spectrum Disorder. Those of you who saw her present at the National Conference in Hobart in 1999 will be delighted to know that she is again visiting our state. We will let you know details later in the year.

On a personal note; many people who read this report in the December issue, have asked about my son's inclusion into secondary school - since the school he was to attend burned down in mid-December. I am glad to say that due to the Principal's enthusiasm and constant optimism in the face of a very difficult situation, there has been a very positive outcome for our family. As I write this, Thomas is attending his second day at Reece High School, which is currently sharing the campus of Devonport High School. The amounts of work done during the holidays to ensure that both of these high schools were up and running for their students, is nothing short of a miracle. The staff at Reece share their Principal's enthusiasm and for us this has been wonderful.

Thank-you to all those people who have contributed to this newsletter, we really appreciate your input.

Rose Clark

### Available from Autism Tasmania

#### **Autism Tasmania Information Kit**

*\$12.00 includes postage for Parents*

*\$17.00 includes postage for Professionals*

**Alert Cards** \$2.00 for 12

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

### Disclaimer

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

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

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

## AUTISM TAS RENEWALS

In the December issue of the newsletter we included a renewal form.

We know that in the Christmas rush, it was most likely put somewhere for "later" and maybe lost.

If you have not yet renewed please do so soon and if you'd like another form, please contact Rachel or Sue (their numbers are on this page)

## WANTED – LIBRARY USERS

Over the past couple of years we have bought many books, tapes – audio and video for the library and very few people take advantage of them. If you have a specific reason as to why you don't access them – difficulty in viewing them, no time to read, would like to know what each book is about before ordering it etc....please let us know. We want this service to be of use to YOU, so YOU need to let us know how to operate the library so it benefits everyone.

Rose

### AUTISM TASMANIA LIBRARY

Books can be borrowed by ringing

North Tricia Bourke 6334 2843

South Roseanne Lay 6244 2540

N W Eileen Prunster 64425405

## Committee Members for 2001

|  |  |  |
|--|--|--|
| <b>President</b><br>Rose Clark   | micknrose@vision.net.au  | 6423 1086  |
| <b>Vice Presidents</b><br>Rachel Hodge<br>Sue Thorogood  | molly@microtech.com.au<br>N/A  | 63443261<br>63622698   |
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## COMMITTEE MEETING

At the last Committee Meeting held in January at Ross, we covered many issues including: Autism Awareness Week advertising, Seminars, and Fundraising, making it a very productive meeting. Attending were representatives from YAST, Giant Steps, the Asperger's Support groups and Autism Platform.

Members are always welcome at Meetings. The next meeting will be held in Launceston on March 24th. If you are interested in attending, just phone one of the committee members in your area

Cheryl

Minutes Secretary

**FOR YOUR INFORMATION**

**Car Restraints.**

Over the past couple of years Autism Tasmania has had enquiries from parents regarding secure car restraints for their child with autism. Recently we acquired a FAS Catalogue which lists various types of therapeutic equipment including car restraints. The E-Z-ON Vest is made in the USA and distributed in Australia by FAS. The vest (which does come in several versions) has a back zipper to discourage the child from opening or removing it. There are accessories which allow assembly of customised versions of the restraints to suit your individual requirements. You can contact FAS by phone, (03) 9587 6766 or 1300 30 35 36 and speak to Judith Hosken, email [fast@enternet.com.au](mailto:fast@enternet.com.au) or look on their website [www.fasequipment.com](http://www.fasequipment.com) or write to 3 Bradshaw Street, Mordialloc, Victoria 3195. Autism Tasmania does have a copy of the catalogue for loan to anyone interested.

**Launceston Community Legal Centre.**

The Launceston Centre at 4 George Street, Launceston has a Disability Discrimination Advocate, who is able to provide information on areas of discrimination against those people with a disability. We received very positive comments from a parent who lives in Hobart who has used this service and wished the information to be passed on. You can contact the service on 63 341 577.

**Launceston Student Workshop Inc.**

Is located at 252 George Town Road in Rocherlea and provides real-life trainee experience to Grade 10 Students. They produce a wonderful array of wrought – iron garden furniture as well as cots, high chairs and other nursery furniture. The show room is open to the public Monday to Friday from 8.30 – 4.00p.m. and the prices are very attractive matching the products produced. It is well worth a visit.

**LETTERS TO THE EDITOR**

Dear Editor ,

I've recently noticed many parents are not aware of the services that are available to them, so I have included a list of some of them. I hope that your readers find it useful

Sue Thorogood

**SOURCES OF SUPPORT**

- 1 **TRANSPORT ACCESS SCHEME**  
Assists people with a permanent and severe disability which prohibits independent access in the community  
*Forms are available from SERVICE TASMANIA or by phoning 131105*
- 2 **CONVEYANCE ALLOWANCE**  
Paid to isolated parents or guardians to help with the cost of transporting students between home and school. (must have to travel at least 5 kms each way by private car)  
*For forms and further information, contact 6233 5265*
- 3 **COMMUNITY EQUIPMENT SCHEME (CONTINENCE)**  
A scheme to help eligible persons within the community toward the cost of continence aids.  
*Contact Marlene on 6336 4133 for further info Closed Mondays –open Tues-Thurs 9-12 and 2-4.30 Fridays 9-11am.*
- 4 **FAMILY BASED CARE RESPITE SERVICES.**  
Provides in-home respite, hosting programs etc.  
*Phone 6331 8188*
- 5 **The PUBLIC TRUSTEE**  
Can advise families about Wills and Powers of Attorney  
*Freecall 1800 068784*

## **WHAT'S ON?**

### **National Autism Awareness Week.**

This week will be held between May 13th-19th. Planning for activities and media releases are underway, but we would welcome any suggestions you may have. As the week falls at the same time as Mothers' Day a slogan incorporating Mothers would be very fitting. Any ideas? Information regarding dates and activities will be mailed out closer to the event

### **Seminars/Workshops.**

In April Wendy Lawson will again be visiting Tasmania. This time her main audience will be those involved with Diagnosis and Assessment (see President's Report on the inside front page). Wendy will be spending two weeks in the state directly after Easter and will be speaking to those working with Assessment and Diagnosis.

Carol Gray will run a workshop in Launceston on 13 August in a jointly sponsored by Giant Steps and Autism Tasmania. Her work in the autism field focuses on social learning and understanding – many people will be familiar with her innovative use of social stories and cartoon conversations Carol was last in Tasmania as keynote speaker at the 1999 National Autism Conference in Hobart. Her workshop is certain to be practical, interactive and great value! Detailed information will be distributed in April.

Autism Tasmania is also organising evenings with a speaker from the Public Trustees Office who will be speaking about Wills, the Power of Attorney and other items parents and carers request on the night. The first was in Launceston on March 8th. Both the South and North-West will have similar evenings during first term.

### **The National Conference – Sept 2001 "Positive Steps Forward".**

In our December issue, we sent out details of this conference and registration details. It is to be

held in Adelaide from September 27<sup>th</sup> to 29<sup>th</sup>, 2001 and is being hosted by the Autism Association of South Australia. Keynote speakers will be Paul Shattock, Pat Howlin, and June Groden - all from overseas and from Australia, Tony Attwood, Bruce Tonge, Wendy Lawson, Lawrie Bartak and Verity Botroff. Please note that if you are thinking of attending this conference that Early Bird Registrations close on July 1<sup>st</sup> 2001.

### **Inaugural World Autism Congress.**

This World Congress is to be held in Melbourne – November 10<sup>th</sup> to 14<sup>th</sup>, 2002 at the Melbourne Convention Centre. The theme is "Unity Through Diversity" and planning for this very large, exciting event is underway. As from February 2001 there is a website you can visit for further up-to-date information, it is [www.autismcongress.com](http://www.autismcongress.com). We will keep you posted with information in further issues of Autisms News.

### **Pilot Project Study into Early Intervention.**

A meeting of this group was held in Hobart on February 26<sup>th</sup>. The task at hand is a very important and time consuming one as a great deal of documentation regarding Early Intervention is being examined. Currently various working parties are looking at best practice in various locations around Australia and elsewhere so that time is not wasted "re-inventing" the wheel. It is hoped to have a program up and running before the end of the year. Another meeting is planned for April 23<sup>rd</sup>.

### **Parent Reference Group**

You will have read a report of this group in the December newsletter. As yet this group has not met in 2001. The meeting scheduled for March 16<sup>th</sup> has been postponed till late April due to the commitments of some of the attendees. The next meeting will be in Campbell Town and Kaye Elphinstone from the Epilepsy Association will address the group. A report will be in the next newsletter.

Rose

## SHORT COURSES/WORKSHOPS

The following information outlines the various short courses /workshops that can be accessed through Disability Services.

### 1 Disability Awareness Short Course

This short course is facilitated by the Information and Education Services, and is offered over a 2 week period in March, July and November 2001. People can attend for an individual session, daily, weekly or for the full 2 week period.

**Target Group:** *People who wish to acquire / or enhance their disability awareness, knowledge and skills, and people seeking employment in the area.*

### 2 "Information and Education Requests"

These requests can include short courses/workshops, for example:

- Contenance;
- Current Disability Legislation;
- Developmental and intellectual Disability Awareness;
- Getting it Down on Paper;
- Grief and Loss;
- Hygiene
- Nutrition
- Parents, Families and Carers;or
- Role of the Support Worker

**Target Group:** *Government and non-government employees, parents, families and carers who support people with disabilities*

### 3 "Disability Services Short Course Calendar"

Short Courses/workshops that will be regularly scheduled throughout the year (are also available through 'Information and Education Requests') for example:

- Challenging Behaviour;
- Chat books;
- Duty of Care;
- Key Concept signing;
- Manual Handling;

- Meal Management; Protective Behaviours; or
- Shaking up the House

**Target Group:** *Government and Non-government employees, parents families and carers who support people with disabilities*

### For further information please contact:

#### South

##### Information and Education Unit Disability Services

St Johns Avenue  
 St John's Park  
 NEW TOWN TAS 7008  
 (PO Box 9, Moonah Tas 7009)  
 Phone (03) 62307600  
 Fax (03)62307605

email [infedu.south@dchs.tas.gov.au](mailto:infedu.south@dchs.tas.gov.au)

#### North

##### Information and Education Unit

John L Grove Centre  
 33-39 Howick St  
 Launceston TAS 7250  
 Phone (03)63364130  
 fax (03)63364131

email [disability.admin.north@dchs.tas.gov.au](mailto:disability.admin.north@dchs.tas.gov.au)

#### North West

##### Information and Education Unit

2nd Floor, Parkside  
 Brickwell St  
 Burnie TAS 7320  
 Phone (03)6434 4103  
 Fax (03) 6434 4122  
 Email: [disability.nw@dchs.tas.gov.au](mailto:disability.nw@dchs.tas.gov.au)

*There is no cost involved for any of the above short courses/workshops*

## WHATS BEEN HAPPENING

### NEWS FROM YAST

*(Supporting Families Using Applied Behavioural Analysis)*

Our year has got off to a great start with a good sized group turning out for our first meeting of the year at Rosemary Rush's home on February 21st. Many of "our" children have had solid starts back at school and more and more schools are welcoming ABA therapists to work with children at school during school hours. Our membership is now over seventy - with families with children as young as two joining us. It seems that earlier diagnoses are happening - to our children's benefit!

YAST - along with Autism Tasmania - is represented on the Education Department's Working Party for the Pilot Early Intervention Program. I am now pleased to report that over the summer a core group of Education Department people has done some important groundwork and we should be hearing more soon. YAST is also represented on the Parents' Reference Group - a group of parents of children with disabilities which reflects on, comments upon and seeks clarification from SEAC - the Education Department's Special Education Advisory Committee. It is reassuring to note that this group is very mutually supportive and has a compassionate and efficient chairperson in Susan Rockliff from the Tasmanian Council of State School Parents and Friends Associations.

YAST is very pleased that the Bowen District - on the Eastern shore of the Derwent River - is hosting two seminars on ABA and precision teaching presented by Leah Climas from Bulleen Heights Special School in Melbourne on March 22 and 23. Bowen has risen to the challenge of inclusive teaching of children on the Autism Spectrum and YAST is thrilled with their commitment and willingness to share information so readily. Kate Slater is the Support teacher and contact at Bowen District Support Service and several YAST members also form part of the team overseeing the initiatives.

Our next meeting is at my place - Lisa and David Minchin's, phone 62 232317 - 4 Lasswade Avenue, Sandy Bay on Wednesday March 21. The focus of this meeting will very much be mutual support as our February meeting, being the first of the year, was

of necessity, full of updates. So come along with news and questions to share over coffee or perhaps something stronger!

Clinical psychologist Jura Tender will be in Tasmania again in mid-March to review and assess children. The Parents Review night will be at Tracy Dillon's, 36 Merindah Street, Howrah (RSVP Ph 62 47 1937) on Tuesday 13th March: "old" parents and any YAST members - whether they be clients of Jura or not - are welcome to share and seek information free of charge.

Real Estate agent and Hobart personality Hank Petrusma is organising a concert featuring singer Patrick McMahon to be held at Wrest Point on April 7. The Petrusma-Reeves Concert for a Cause will feature Hobart band, Giant Hamsters in the first half and Patrick McMahon, will be the guest artist for the second half. Former Miss Tasmania, Angela Potter, will be giving a personal insight into autism during the night and there will be a collection in aid of YAST at the end of the evening. Chickenfeed has already made a major donation as sponsors too. Our thanks go to Hank and Angela for their interest and involvement.

Phone Lisa Minchin closer to the event for more information.

I hope you all have children now relatively "settled" at school and are finding the energy to care for yourselves as well. Take care,

Lisa Minchin, President

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### Calendar of YAST Events

**21 March** Lisa and David Minchin's  
4 Lasswade Ave, Sandy Bay 62 232317

**18 April** Shane and Tracy  
36 Merindah St, Howrah 62 471937

**16 May** Karen's  
89 Grove Rd, Glenorchy 62 732684

**20 June** Anita's  
12 Allambee Cres, Glebe

**18 July** Judy's  
24 Laguna Place, Goodwood, 62 732676

## NEWS FROM GIANT STEPS

Giant Steps has started the year on a positive note. We welcome Rebecca Claridge as our new Speech Pathologist and one new student has also joined us, fitting in to our Adolescent group very well. It was surprising to hear during the holidays from a couple of prospective parents some misunderstandings of how Giant Steps operates. There seems to be a belief in the community that parent fees are around \$20000 for each child. In fact, fees are only a fraction of that and the figure has not changed since 1996. Also, the days when each child had a 'shadow' have long gone. Today, we retain our strong team of therapists and the children are encouraged to work with a range of Therapy Assistants rather than build dependence on just one. Staff to student ratio is close to 1:1 so we are confident that our children could not be better served. We always suggest that people come to visit us to form their own opinions of what we do rather than listen to what other people believe might be the case. If you would like to know more about Giant Steps, please give us a ring.

Many people have commented that we are often very isolated in Tasmania so, when an international 'expert' visits our shores, we should take the opportunity of meeting with that person to get a flavour of what is happening in other parts of the world.

One such visitor during the summer was Polly Yarnall, who runs Autism Consultancy Services in the United States of America. Her son lives in Hobart and Polly comes often to visit. When Giant Steps heard that she was here for Christmas and New Year, we decided that it was worthwhile for our Therapy team to meet her as a group.

We found the meeting fascinating and are looking at ways to maintain the contact in the future. Polly is based in California's Central Valley, 90 miles east of San Francisco. It is an agricultural area with vast orchards and a population which includes itinerant workers and well-established and wealthy landowners.

Polly works with local school boards as a consultant and is often featured as a speaker at various Autism conferences. She works particularly with the Future Horizons group, with such well-known presenters as Tony Attwood and Temple Grandin. She has been employed for a number of years by the University of North Carolina as a trainer for their TEACCH program, in the United States and Britain.

She has a number of current projects, including working with a group of autistic students in her local area to 'wean them off' dependency on their aide. She believes it is important to work towards developing independence and finds that the intensive one-to-one of much early programming in autism needs to be countered by a later focus on independence.

Polly believes that the organisational structure of the TEACCH program leads to students gaining independence more quickly.

She also works in Autism research, particularly with Margaret Baumann of Harvard who is looking closely at the structure of the brain in autistic people. She showed us a presentation she has prepared on the ways in which the autistic brain differs from that of neuro-typical people. For example, there are differences specifically in the frontal lobe which can help to explain the difficulties those with ASD have with organisation. In the speech areas of the brain, too, there are differences and also in the cerebellum where differences in the structure of particular neurons point to difficulties with transmitting 'messages' from one part of the brain to another.

This new brain research has implications for the learning styles of ASD children and it is vitally important that we understand how best to structure the learning environments of our classrooms to give our children the best opportunities to learn.

Polly is a great fan of the TEACCH program and is kept busy working with the team from the University of North Carolina. She talked to us about some of the recent developments and principles of the method. It has been adopted by the NAS schools of Great Britain as well as more and more educational districts in the USA.

One very important piece of information she passed on: in most states of the USA, governments have accepted responsibility for the appropriate education of ASD children. This means that a child with ASD will be funded to a level necessary to maximise his learning opportunities. An accepted figure of \$48000 - \$50000 per year is the norm in the USA, and children in private schools attract around \$75000. In addition, a similar sum is available for each child for transportation to the most appropriate school. Governments in Australia have a long way to go if they expect to match world standards in the education of special needs children.

John Christie *Principal*



## WRITING SOCIAL STORIES

Many readers of Autism News will know of Carol Gray, who was a keynote speaker at the 1999 National Autism Conference in Hobart. Carol, Director of The Carol Gray Centre for Social Learning and Understanding, developed the concept of social stories to enhance social understanding in children who have an Autism Spectrum Disorder.

Last October, in Melbourne, she presented a two day workshop entitled FROM BOTH SIDES NOW – How to teach social understanding. A number of staff from Giant Steps participated, as did two parents, Penny Cromarty and Ros Ward.

Carol Gray is a most captivating speaker, who used personal experiences and anecdotes, often humorous, to illustrate all aspects of the workshop. The aim was to teach us how to write some basic social stories.

Carol took pains to describe the rationale behind writing social stories, emphasizing that any social interaction (and therefore social understanding) involving a person with ASD requires at least two people, ie. the person with ASD and at least one other. Carol asserts that the social impairment is shared, that the non-autistic person is part of the problem associated with social understanding, and therefore needs to be part of the solution.

She urged us to think about our own social ability, and to consider the non-verbal and other “hidden” clues that “neurotypical” people use to get the gist of a situation.

Carol explained that the goal of a social story is to teach social understanding. It addresses the needs of people on both sides of the social equation. While the primary aim of a social story is not to change the behaviour of the recipient of the story, often an unsatisfactory behaviour changed for the better, because as a result of a successful social story, a person may have greater social understanding.

Carol then got down to the nitty-gritty of

writing the social stories. She stressed the importance of using positive language, and of clearly stating desired responses. Carol explained that social stories are composed of a particular blend of descriptive, perspective, affirmative and directive sentences. The workshop participants had opportunities to practice these and to read them aloud, for which Carol insisted they receive applause. She talked about the need for literal accuracy and explained the basic social story ratio of 0-1 directive sentences for every descriptive, perspective or affirmative sentences.

Carol emphasized the need to use concrete east to understand text, enhanced by appropriate visual supports. In fact, she said “if the child can’t see it, then you haven’t said it “.

She also stressed that social stories use text and illustrations that reflect an understanding of the reader’s cognitive ability, reading skills and attention span.

There was plenty of opportunity for us to improve on some poorly written stories that Carol presented. Getting them just right was, in fact, much trickier that we had realized, but Carol told us that when we had written 500-600, then they would come quite easily!

Based on information and references from Carol Gray’s workshop, Ros Ward and Penny Cromarty presented two sessions at Giant Steps. called *Enhancing Social Understanding- An Introduction to Social Stories*, Ros and Penny spoke to a group of parents and then to a group of staff about several aspects of Carol Gray’s workshop and both groups have started to write some basic social stories.

Penny Cromarty

## FEATURE ARTICLES

### STANFORD AUTISM GENETICS PROJECT

*Dept. of Psychiatry and Behavioural Sciences & Dept. of Genetics, California US (www-cap.Stanford.edu) – Progress report – July 2000*

Many questions are asked by families regarding genetic factors and Autism Spectrum Disorder. Research to locate the group of genes that may be involved are being conducted by a number of teams around the world. In Australia, the Centre for Clinical Research in Neuropsychiatry at the University of WA is conducting the Australian component of the worldwide Stanford Autism Genetics Project, in which a number of Australian families has participated (contact (08) 9347 6429). A summary of a report from the Stanford team appears below.

One of the objectives of the Stanford team is to find the genetic locations which may influence the susceptibility to develop autism. This has involved a number of related studies, three of which have been published in the last two years. Two of these studies focussed on specific genetic locations identified by other researchers as possibly linked with autism. The third study was a complete genome screen with DNA samples from 139 families with two or more siblings with autism.

A single dominant gene does not cause autism - it is not a simple pattern of inheritance. The finding of a specific location for a group of possible genes continues to elude researchers. While twin and family studies strongly suggest the involvement of genetic factors in autism, no researchers have located any definitive regions of the chromosomes that have strong associations with autism. As data is being gathered by researchers world-wide, the process of analysing and evaluating results for specific areas of the human chromosomes continues to be a challenge. Each study gives more information about areas to investigate.

#### The Immune Connection

There have been studies that suggest that immune imbalances might contribute to the abnormal development of the brain. Two possible explanations are a viral process or an auto immune process affecting the central nervous system. Investigators have located some genes

that affect immune response in the human leukocyte antigen (HLA) complex on chromosome 6. Is this the area where the genes related to autism reside?

The team examined 97 sibling pairs with autism from 90 families with the hope of finding greater than 50% sharing of the appropriate genetic material. There was no significant excess of sharing found. However, the team cannot rule out the possibility that this region (HLA on chromosome 6) may influence the development of autism for a subset of families with significant auto-immune abnormalities.

#### Chromosome 15 Studies.

Earlier studies have suggested that the chromosomal region 15q11-q13 may contain a gene or genes that play a role in the susceptibility to autism. The Stanford team conducted a search of eight markers in this region using 147 sibling pairs with autism from 139 families. Again, results did not show evidence of increased sharing (i.e. greater than 50%). Whilst this study of a large sample did not show any greater than expected pattern of sharing, other smaller studies of singleton cases have. The Stanford team conclude that this region on chromosome 15 may be related to the susceptibility to autism in a smaller number of families. The area is therefore worthy of further examination.

#### Genome Screen.

The larger project doing complete genome screens did not reveal any greater than the expected 50% sharing of genetic markers between affected siblings. Whilst the team found no evidence for genes having a major effect, they still believe that there are regions on the human genome having a moderate effect leading to a susceptibility for autism. They hypothesize that autism may be caused by 10-20 genes or more.

#### The Future for Genetic Research.

The Stanford team is optimistic of finding some answers for the genetic cause of autism question. They are currently planning a screening of families with children with autism in "founder" of genetically homogeneous populations, such as the Amish and Mennonites.

Reproduced with permission from Autism News Victoria, December 2000

## **SURVIVING THE SUPER-MARKET**

*taken from HELP CORNER Autism Association of WA Inc Newsletter Sept 2000. Reprinted with permission*

**Q** My son, "Matthew" is 6 years old and every time I take him to the supermarket for the week's shopping on Saturday morning he is like a wound up engine ready to 'go off'. As soon as I get through the door, he makes a beeline for the aisle with the sweets. When I let him take a packet of marshmallows and put them in the trolley, he throws a whopper of a tantrum and wants to eat the marshmallows there and then. (He does not understand the concept of waiting to pay. I am not sure that he even understands what the words mean). We usually have to abandon shopping at this point. However, there is a bigger dilemma yet: when we get to the check-out there is usually a queue. My son screams and has no concept of waiting in line. If I try to leave, however, without the marshmallows, he will become a dead weight screaming and kicking. Even if I manage to get him to the car and get him inside, he will be in an angry mood for the remainder of the day. Will I ever be able to go shopping with "Matthew"?  
Signed: "Jean", Perth Metro

**A** Dear "Jean"  
There are a number of things you will need to consider when taking Matthew to the supermarket. In fact, you have highlighted these in your letter:

- *Matthew is obviously very agitated when he gets in to the supermarket.*
- *Matthew does not understand why, after you have told him he can have the marshmallows, he is not allowed to eat them (he does not understand the concept of paying for the sweets).*
- *He does not understand the concept of waiting in a line (queue at the check-out).*

The good news is that with appropriate teaching you will more than likely be able to take Matthew shopping in the future. There is a need, however, to teach Matthew skills which he does not yet have, which will allow you to take him shopping without incident.

To begin with, Matthew's behaviour e.g. his agitation, his

tantrums, are not a wilfulness or an inevitable part of Autism. The behaviour being demonstrated in the supermarket is communicating a skill deficit. With Matthew's limited understanding of communication and social conventions, he is becoming very frustrated and confused. Your action of taking the marshmallows off the shelf is on the one hand saying to Matthew, "yes, you can have the marshmallows". Then when he tries to open the packet and you take the marshmallows away, you are now saying, as far as Matthew is concerned, "no, you cannot have the sweets." It is not difficult to see how confusing and frustrating this is for Matthew. So, with this in mind, we need to teach Matthew, in an unambiguous manner, the concept of "wait", as it relates to supermarket shopping.

### **Recommendations**

- 1) To ensure the greatest likelihood of success, start with taking Matthew to the supermarket at quiet times rather than at week-ends. You may eventually be able to take Matthew during busy periods but, to begin with, you need to teach under the least over-arousing conditions possible. We want Matthew to focus on what is being taught without, in the early stages, having to deal with all of the other things which will agitate him e.g. crowds, noise etc.,
- 2) Find the quietest times at your supermarket, or find a small quiet local supermarket. Plan to go at least three times a week. Remember, consistent repetitive meaningful routines are a critical factor in teaching a new skill. Do not plan, in the initial stages, to undertake family shopping on these occasions.
- 3) Go to the supermarket, and assist Matthew to push the trolley quickly to the marshmallows. Quickly take the marshmallows, place them in the trolley, and at a very quick pace make your way to the checkout while repeating to Matthew (as he grizzles, no doubt) "going to pay the lady". Go to the checkout without a queue (this should not be difficult if you choose your time right). Quickly pay and give Matthew a marshmallow.
- 4) Continue with this routine several times throughout the week, until such time as Matthew stops grizzling when you put the marshmallows in the trolley. This will indicate that he has grasped the concept that there is a step between getting the sweets off the shelf and receiving one to eat.
- 5) Having grasped the routine that getting a marshmallow in the supermarket involves placing a packet in the trolley, going to the checkout, and paying, before you receive one to eat, you can now begin to expand the routine.

*(Continued from page 11)*

6) Go to the supermarket and get the marshmallows as usual. However, instead of going directly to the checkout, go to a nearby aisle, and take one additional item. Reassure Matthew repeatedly that you are going "to pay the lady". At first you can expect Matthew to be a little upset by the change to the routine, but he will soon learn that the routine ultimately ends the same i.e. he gets a marshmallow after he goes through the checkout.

7) Continue to extend the routine by a couple of additional shopping items. Once the concept of shopping (putting things in the trolley, going through the checkout, getting a marshmallow) is understood, you can make a leap to undertaking some "real" shopping for the family. Start with a small trolley-load, and gradually build on Matthew's understanding and tolerance.

8) When you have sufficiently extended the routine to being able to shop for what you need, you may now wish to introduce Matthew gradually to busier periods. Before you do this, you may wish to shop with a friend and ask your friend to go in front of you through the checkout. In this way, Matthew will get used to queuing, initially with only one other person in front. Gradually, you are teaching Matthew that while the routine is changed, he still gets his marshmallow,

which is what the whole exercise means to him.

*The important principles involved in this teaching exercise are:*

- *Teach a new skill in the environment in which the skill will be used.*
- *Modify the environment to take account of the child's sensory difficulties with noisy busy environments (in this case, since you cannot directly modify the environment, you can achieve the same result by going to the supermarket at a quieter time).*
- *Teach a new skill in the context of a meaningful routine. Systematic routines assist the child to understand what is expected of him/her and what happens next. Routines reduce the confusion of a world the child finds difficult to understand.*
- *Ensure frequent and repeated opportunities in which the child can learn mastery of the skill.*
- *Ensure that the skill being taught is rewarding and meaningful for the child.*
- *Make sure that the steps involved in acquiring a new skill are defined, and a planned approach to teaching each step is plotted in advance.*
- *Only teach the child one step at a time.*
- *Expand the learning routine as the child masters each successive step being taught.*

## ASPERGER'S SUPPORT GROUPS IN YOUR REGION

**Asperger's Southern Support Group**  
Contact Roseanne Lay on ph. 6244 2540

**Asperger's Northern Support Group**  
Meetings are held at 1:30pm at Walker House, Newnham on the last Saturday of each month Phone Rachel Hodge 6393 7183 for details

**Asperger's North Western Support Group**  
Meetings are held at Leighland's Christian School, Leighland's Ave, Ulverstone on Contact Eileen Prunster 64 425405



## AUTISM PLATFORM

*For more able adults with an Autism Spectrum Disorder and their parents*  
An Apology

For those of you who have had difficulty contacting us, our sincerest apologies. Your representatives in the North and South have both relocated. Please make a note of the new telephone numbers. Monthly meetings have resumed.

|                 |           |
|-----------------|-----------|
| South.....Jan   | 6272 1049 |
| South.....Irene | 6278 2394 |
| North.....Paula | 6397 3088 |

## BULLYING MYTHS AND CHILDREN WITH ASD

by Carol Gray

Our thanks to Carol Gray and Jenison Public Schools for permission to reprint the following extract from *'Gray's Guide to Bullying – Part I: The Basics'* written by Carol Gray and appearing in the Winter 2000 edition (Volume 12, Number 4) of *'The Morning News'*, published by Jenison Public Schools, Michigan, USA. and protected by a 2001 copyright.

*'Gray's Guide to Bullying'* addresses bullying in light of its frequent targets: children with ASD. Part I (released in January 2001 in Australia) looks at the facts and myths of bullying, changes in attitudes, the development of anti-bullying programs and the unique diagnostic characteristics of children with ASD which potentially places them at "high risk" for bullying. Traditional definitions of bullying do not represent the needs of children with ASD - a new inclusive definition of bullying is proposed.

*Bullying is a part of The Real World. In Part II: The Real World* (appearing in the next issue of *'The Morning News'*, available in the Australia in April 2001), a new definition of *The Real World* makes effective interventions for bullying possible.

See the flyer in this issue for direct subscription details of *'The Morning News'* in Australia.

As I raised the topic of bullying during the last year, many parents and professionals expressed concerns and advice. Occasionally, I have replayed these conversations – and re-read the letters and emails. Like a Polaroid photo that gradually becomes clearer, I have identified five myths that surround the topic of bullying and children with ASD. Many were some of my own that didn't survive the development of this guide. As I learned and considered new information, they began to look like myths when placed in competition with the facts.

1. *Just wait until Angie gets to the junior high – they will eat her up.* This one tops the list, both in terms of prevalence and social danger for children with ASD. It represents the myth that it is inevitable that this child will be bullied. While parents and professionals predict with incredible accuracy when and where bullying situations may occur, that precision is matched by an implied acceptance of "horrible things to come". Bullying is not a tornado, earthquake or its social equivalent. Bullying – regardless of the vulnerability of an individual – can be effectively addressed. To believe otherwise is to *ensure* that bullying is an inevitable secondary social symptom of ASD.

2. *If Angie wouldn't insist on talking about fish or wearing those clothes with cartoon characters all the time, she wouldn't be targeted by children who bully.* Many of those working on behalf of children with ASD confuse the reason a child is targeted by a bully with a *bullying topic*. Though not discussed in the general bullying literature, distinguishing between the two terms is critically important, especially with a population of children who have such unique social characteristics, mannerisms and special interests.

A *bullying topic* is the subject matter of a bullying interaction. For example, bullying topics include (but are not limited to): aspects of appearance, personality, personal interests, personal relationships, mannerisms and unusual or distinctive characteristics, skills or abilities. Thus, the topic behind the statement, "You fish nerd" is an extensive knowledge of fish. Many parents and professionals believe these traits – these *topics* – are the *reason* a child is bullied. This isn't true.

The *reason* Angie is bullied is similar to the reason every other child is bullied: she is frequently alone. Every expert on bullying agrees: the majority of children who are bullied struggle with social skills and have difficulty establishing friendships. Over the last several years, this author has observed several students with ASD as they have progressed

(Continued on page 14)

through their school career. Despite outstanding and – in some cases – irritating traits, a few have sailed through the years untouched by bullying. In each and every case, the student has had a friend who is well-liked and respected and free from close association with peers “at risk” of getting into trouble or confrontations. Dr Liane Holliday-Willey, an adult with Asperger’s Syndrome, writes about a friendship like this in her book, *Pretending to be Normal*:

“I am amazed my peers put up with me and my peculiarities. Truth be known, they may not have, had it not been for a very good friend of mine named Craig. This friend was very bright and very funny and very well-liked. With him by my side, I was given an instant elevated status among our group and even beyond. He had been my friend almost forever and over the years he had become almost like a guardian to me .....In subtle and overt ways, he would show his support for me by saving me a seat at lunch, walking me to class, or picking me up to take me to a party. He fixed me up on dates, made me laugh when my nerves started to twitch and kept me company if I was alone in a crowd .....Craig jumped to my rescue even before I knew I needed to be rescued.” (1999, pp. 40–41)

4. *That’s interesting ...still, let’s get Angie new clothes and teach her not to talk about fish.* There’s a children’s book that every parent and professional concerned about bullying should read. Pinky, Rex and the Bully (Howe, 1996) challenges our tendency to respond to targets of bullying with advice to change, to “... don’t do that ...”, “... don’t wear that ...”, or “... don’t take that to sharing time”. Here, another important distinction must be made: the difference between *Target Coaching* and *teaching social understanding*.

*Target Coaching* refers to efforts by adults that are well intentioned but carry an underlying message that “who you are is not okay”. For example, consider Angie with backpack stuffed with fish books and eight pamphlets from Chicago’s Shedd’s Aquarium. That’s okay. It’s also okay for Angie to move her hands in a unique way when she is excited or to decide each day to wear cartoon clothing. Efforts to make a shy child an extrovert, to get Angie away from classroom aquarium during indoor recess, or to make anyone less “tease-able” by changing a characteristic that is based on personal choice are all examples of Targeted Coaching. Targeted Coaching can diminish self-esteem, especially among a population that may be unaware of the good intentions of adults.

*Teaching social understanding* refers to instruction in social concepts and associated skills, for example, helping a child to first understand the need for turn-taking in a conversation, then teaching and practicing those skills. For Angie, who desperately wants friends and loves fish, one social understanding objective is to help her understand that to keep others engaged in conversations, it is important to balance their high interest topics with her own. Sharing information about fish is okay, it may lead to a career. Knowing when and how to share that information with others is an important social understanding.

5. *Angie attended the anti-bullying program at school and she’s better now at reciprocal interactions. If she’s still bullied, it’s her problem.* Adults may assume that there is just “so much they can do” to ensure a child’s physical and emotional safety at home, school or in the community; beyond a certain point, it’s up to Angie. The inaccuracy lies in what adults define as “... a certain point”.

Adults have to get directly involved throughout

(Continued on page 15)

(Continued from page 14)

Angie's life. "A certain point" exists at the end of a comprehensive, lifelong effort to ensure comprehensive, anti-bullying education programs, sensitive supervision and individualised instruction. In addition, the research indicates that the profile of bullying – its format and content – is likely to change as Angie grows. Without command of the intuitive social information of her peers, Angie is not likely to independently identify the changing "face" of bullying or modify her responses accordingly.

5. The school needs to increase supervision on the playground at Angie's school. The research is very clear on this one. Olweus, one of the most well respected international experts on bullying, has concluded that increased adult supervision is the single most powerful factor to deter bullying. Logically, a parent may request that supervision in areas prone to bullying: hallways, bathrooms, lunchrooms and playgrounds, be increased. An important consideration may be overlooked. A child with ASD may be misunderstood by adults who – without any background information of training – respond to her at face value. For example, unaware of the characteristics of a pro-active target of bullying (described later), an adult may respond with statements or consequences that are likely to be ineffective if not prone to "add insult to injury". Consider this example:

"I am a special education teacher. The other day during lunch, I noticed the lunch room assistant marching Jacob to the office, pulling him by his shirt. Jacob was guilty of "circulating" too close to other students. They asked him three times to "go away". Giving up, they tripped him. Jacob fell to the floor and cried. The lunch room assistant "saw the whole thing". When I asked her which child had tripped Jacob, she wasn't sure. It didn't

matter. "Jacob," she said, "had no right to irritate the other students".

In Jacob's case, increasing adult supervision may increase the likelihood of being misunderstood. Providing trained and sensitive supervision, placing an increased number of people who understand bullying and it's unique profile and implications for children with ASD, is more likely to achieve the results Olweus described, for children with ASD.

The trouble with some of the common myths and assumptions surrounding bullying and children with autism spectrum disorders is that, if believed and acted upon, they may actually increase the likelihood that bullying will increase. For example, believing that: 1) bullying is inevitable; 2) the child with ASD has to learn to be less "teasable"; 3) general education anti-bullying curriculums – without supplemental effort – will effectively teach children with ASD new responses to use with children who bully; or 4) increased supervision will fix everything, is counterproductive. Where myths can enable inaction, information makes inaction inexcusable.

*Reprinting arranged by Giant Steps through their Australian distribution arrangements for 'The Morning News'*

*These useful cards are available from Autism Tas. For \$1.00 for 12. Keep a few in your purse or wallet to hand out at those times you need to explain you child's behaviour*

Autism Spectrum Disorder is a life-long disability due to some form of brain disorder, the cause of which is unknown. About one in one thousand people are affected. Autism Spectrum Disorder prevents people from properly understanding what they see, hear and otherwise sense: as well as affecting their ability to communicate, learn, interact with others and behave appropriately.



For more information contact:

**AUTISM TASMANIA Inc.**

P.O. Box 1552  
Launceston 7250

Autism Tasmania's phone number  
is in your white pages

## MARY'S STORY

*A summary by Paula Barnes of an article in a recent edition of: The Weekly Telegraph Issue No 498 Health.*

Mary Robinson lives in Cornwall, England and has six children between the ages of three and thirteen, five of whom are autistic. Her life is indescribably difficult as she battles to cope with the mayhem caused by children who do not play together but fight. Mary Robinson regularly faces constant wet beds and house repairs whilst coping with her children's challenging behaviours.

"The one thing she cannot do is relax. Thirteen year old Claire could be wandering off, oblivious to danger; 11 year old Tyson might be trying to hatch raw eggs by sitting on them and Jordon, 10, could be in one of his violent moods. Hayden, nine, who cannot speak, will be screaming for her while three-year-old Leah is showing her toy for the millionth time.'

With Mary's husband, John, they take the family on occasional outings to nearby amusement parks or an animal sanctuary. Predictably they are met with disapproval from others.

Mary's children were apparently normal at birth but something occurred to cause their development to regress. She believes strongly that, the MMR vaccine is to blame for her children's autism and criticises the government for it's 3 million pound campaign declaring the MMR as safe.

Mary's daughter, Donna is the eldest of her children and the only one not to receive the triple vaccine which was then, unavailable. Donna is not autistic and lives with her grandparents. According to the report, other causes for autism in her children, can be ruled out. After the birth of Jordon she had his and her own genes tested, "no problem was found," neither was a history of autism found in their families. As a baby, Hayden was given a brain scan and no abnormality was detected; his development was normal until the MMR vaccine. A similar pattern occurred following the birth of her daughter, Leah.

Mary is angry because she believes the medical profession were developing theories regarding MMR and a possible association with autism but did nothing to advise her. The discovery of an article in a magazine alerted her to this possibility referring to a similar case concerning a woman with three autistic sons and a reference to MMR vaccination. Mary now has legal representation.

Married a number of times, with devastating consequences, Mary met and married her new husband, John, about two years ago. John, who has a bad back and unable to work, finds the children difficult because of his disability and inability to run after them but he affords Mary 20 minutes respite so she can eat her dinner alone, in the bedroom.

In a short article alongside the story of courageous Mary Robinson, James Lefanu states that, "There is a view, propagated by the health department, that the research conducted by Dr Andrew Wakefield at the Royal Free Hospital, London is "flaky", as it has not been substantiated by other scientists." This is not the case. Dr Wakefield's observations are based on investigation and assessment of 170 children with a combination of autism and bowel problems that up to now have never been described - and which many parents believe is associated with the MMR vaccine. - The attempts to refute his findings are based not on direct experience with such children but rather statistical techniques that appear to show the vaccine is not implicated...and fails to take into account autism is 4 times more common...than ten years ago and the type experienced by Wakefield's patients -coming after a period of normal development -is also much more frequent.'

The article by Lefanu continues to argue that irrespective of whether MMR is responsible for some cases of autism, Dr Wakefield is the only doctor in Britain investigating the problem and that more funding was needed to continue the research.

Paula Barnes.



## THE SCIENCE SHOW

*Is Autism beginning to have a bigger profile? It was refreshing to hear recently two programmes on the ABC Science Show dedicated to Autism Spectrum Disorders.\**

The programme in January combined personal interviews with those who had autism and the parents of people at different ends of the autistic continuum with the views and shared experiences of Drs Judith Gould and Fiona Scott.

By way of introduction, we listened to Ros, described as severely autistic, talk about her personal understanding of autism and how it impacts upon her life. Encouraged by the interviewer, Ros told us that she has problems with social situations and communication.

Despite having an extensive vocabulary she said that, basic things which people ask her, she often does not understand.

"Often it appears that I am being deliberately annoying, cocky or pretending to be smart but I take things incredibly literally. I often get myself into a mess"

Ros went on to say that sometimes she would be too scared to go to certain places.

A pull-toward-you-door instead of a push-away-door could be enough to throw her into confusion. Sometimes Ros would find herself stamping on her front door mat in an attempt to drive the autism out. With help from her parents, Ros has learned many of the social rules of behaviour and with help manages to live on her own.

In contrast we heard the mother of sixteen-year-old Belinda describe her daughter's self mutilation; biting and beating herself. Hospitalised at three years of age, for incessant crying, Belinda was returned to her mother who listened, for a month, to her child's relentless sobbing unable to pacify her.

Dr Judith Gould of the British National Autistic Association outlined the key features of autism, that is, impairments in social interaction, communication and imagination and added that if people had these difficulties they were usually associated with highly repetitive behaviour patterns. Dr Gould said that there were many manifestations of the autism spectrum and

that the core impairments and the repetitive behaviour patterns have to be present to make the diagnosis.

From a new multi-disciplinary service at Cambridge University, Dr Fiona Scott explained that there was some blurring about just where autism began and ended, describing people at both ends of the continuum. She said that at one end there was the person who shut themselves away, who were mute and had no imagination at all - perhaps tearing up pieces of paper or rocking to and fro. She then went on to describe the other end of the scale, where the person is more capable but who still does not understand the social world and might have bizarre ways of behaving. These people often have normal or above normal intelligence levels, Dr Scott said, but due to their inflexibility of thought they might develop obscure obsessions, for example lamp-post numbers or dinosaurs.

Asked about the prevalence of autism, she said that in its classic form autism occurred in 10 in 10,000, 75% of whom would have an accompanying learning disability. She said, however, that if one were to look at the entire spectrum the figures could be as much as 1 in every 200 people. Within this group there would be those with Asperger Syndrome who are usually very intelligent and may have amazing savant abilities in such things as math, music and art BUT cautioned that they all have severe problems with communication, social interaction and understanding the commonplace rules of daily life, particularly where it related to understanding how you behave with other people.

The programme, at this point, was injected with an all too brief, musical interlude. The music of Debussy played by Mark Bishop, who has Asperger Syndrome, had the potential to reform the most ardent self proclaimed of classical music haters. I am among those who rejoice in classical music, but I witnessed a tear escape the eye of a confirmed pop fan who, up until now has refused to lend a warped ear to such "stuffy music" with a dismissive wave of the hand and a misguided turn of the walkman switch. But I digress.....

Mark's father spoke of his son with pride. Like others in similar situations he had asked himself what he could do to make his son better. When probed he said that sometimes it needed faith and sometimes you needed to be blind. According to Mr Bishop his son had only shown his musical flair within the last six years

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*(Continued from page 17)*

and people began to suggest to him that it might be an idea to 'do' a concert. Mark has been received well by audiences and Mark has had invitations to play from many places throughout the world. Mr Bishop said that one of the spin-offs from his son's concerts was the improvement Mark had shown communicating. The more people engaging him in conversation the more able Mark has become in replying although Mark's father cautioned that people should remember that Mark has only a vocabulary of six or seven hundred words, although this has doubled in the past five years.

Dr Fiona Scott was re-introduced and spoke briefly about some of the lines of research she and her colleagues were following. She said that when looking at brain scans they do not look at one area of the brain and see a distinct area which is different in people with autism but they have been looking at the frontal cortex and believe that this area is implicated in autism. She asserted that there appeared to be some differences in an area of the brain called the amygdala, in evolutionary terms a young area and believed to control social behaviours and social aggression. Dr Scott said that genetic markers had also been identified but '..... the whole picture was probably more complex.'

Following a segment, which referred to a continuing lack of knowledge and understanding in some communities about autism spectrum disorders, Dr Judith Gould said that early, accurate diagnosis was essential to enable appropriate interventions and strategies to be implemented. She spoke briefly about DISCO, a diagnostic tool consisting of a three hour long interview with parents. This interview sought details about pregnancy, birth and early childhood. She said that DISCO had also proved to be useful in picking up other abnormalities, too.

Returning to the issue regarding the possible cause(s) of autism, Dr Scott illustrated the different ways different people have of understanding the world. Some, she said, were better with physical things, were good at maths and reasoning about physical things choosing to become engineers for example whilst others chose jobs as teachers or within social welfare because they were better with things concerning social interaction. She went on to say that there was some evidence to suggest that fathers and grandfathers of autistic children were involved in less social occupations. When asked whether this might be indicative of gender involvement, Dr Scott replied that 4 out

of 5 people with autism will be male. When looking at the larger spectrum this could be 9 men to one female. Fiona Scott explained that some believe that there is a psychological propensity for men to have the brain type associated with a preference for things physical whilst the female brain type is orientated towards things requiring better social understanding. Scott said that this wasn't always the case, of course.

There was some speculation, Dr Scott said, that hormone levels at the time of conception may be involved. They knew that testosterone has an effect on brain development, that the more testosterone the better one's spatial ability. She pondered the possibility that hormones might have something to do with the resultant male or female brain type.

Toward the conclusion of an interesting and thought provoking programme, Dr Gould reiterated the need for more research and continued by saying that she believed that the world would be a dull place indeed if it were not for those with autism; believing that those we revere as geniuses have probably had Asperger Syndrome.

Paula Barnes

*(\*disclaimer: I endeavoured to be accurate in my retelling of this programme. If there are errors, they are not deliberate and I confirm that this is the essence of the story as I understood it.)*

## Deadline 18th May

The deadline for the June issue of  
Autism Tasmania will be **18th May**  
Please forward your copy to Cheryl Scott  
on [cscott1@vtown.com.au](mailto:cscott1@vtown.com.au)  
or phone 63448015 a.h. to make alternative  
arrangements

### DEADLINE

Thank you to everyone who responded to this issue's  
deadline so promptly.  
The June issue's deadline is two weeks earlier and cannot  
be extended,  
as I will be interstate during June.  
As the newsletter takes about 2 weeks to put together, it is vitally  
important to get your copy to me by May 18th (or earlier)  
Many thanks  
Cheryl (Editor)