



Autism News

Newsletter of Autism Tasmania Inc.

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Autism Tasmania Committee

President	Rose Clark	6423 1086	Committee	Lisa Minchin	6223 2317
Vice president	Jenny Vince		Members	Liz Maddern	6435 2021
Secretary				Julie Fyfe	6362 3189
Treasurer	Rosanne Lay	6244 2540		Kathy Gill	
				Rachel Evans	

From the President

The major announcement, as we go to print, is the Commonwealth Government's agreement to provide further funding for Tasmania's Giant Steps program in Deloraine. The decision is very positive news for service provision in the State and will enable the Centre to run to the end of the 1998 school year. Giant Steps has just finished its third year of operation.

The past couple of months have been extremely busy for the Committee and positive feedback is always appreciated. At the recent presentation in Launceston by Louise Ulliana, I was approached by a parent who made enthusiastic comment about the raised awareness of Autism Spectrum Disorder in the general community. This comment is particularly pleasing as raising awareness is one of the major aims of Autism Tasmania. The recent activities of National Autism Awareness Week again put Autism Spectrum Disorder in the limelight.

August 1999 is the date for the next National Conference to be held in Hobart. Organisation is well underway with many committee meetings being held in Hobart so that we can deal with conference details. Our next Committee meeting will be on 11 July in the capital, beginning at 10.30am. It will be a full day, with conference items first on the agenda. If you would like to attend any of our meetings, please contact a Committee member for details.

We welcome Kathy Gill and Rachel Evans who have both recently joined the Committee. Unfortunately, Mark Ward has resigned, after continuous involvement in Autism Tasmania since the very beginning. Mark was inaugural President and has made a major contribution over the last 5 years -

we will miss his experience and thank him for the progress made through his involvement.

If you would like to be involved, please read the details of the AGM in this issue. There is a nomination form included as part of this posting. We need realistic, dedicated people to fill the vacancies on the Committee. We look forward to seeing you at the AGM.

Cheers,

About this newsletter

The focus this issue is on siblings. We have included articles on siblings, from siblings, sibling support advice, titles and resource information for more help and information. If you know of other resources - books, articles, service providers, etc. - please let us know and we will publish the details in later issues, for everyone to share.

Also in this issue is newly available information of Australia-wide research into the Genetics of Autism, from the Centre for Clinical Research in Neuropsychiatry. The project is funded by the National Health and Research Council, The University of Western Australia and the Apex Foundation Trust for Autism. For those of you interested in participating in the research project, we have included an insert for you to complete.

Thank you to Ros Ward

Until now, Ros has produced every issue of Autism News since the inception of Autism Tasmania - often singlehandedly researching articles, typing, laying out, collating, printing and mailing.

By any measure, this is a tremendous achievement and we thank her for extraordinary dedication and commitment to autism in Tasmania.

National Autism Awareness Week

Once again we participated in this week aimed at raising community awareness and knowledge of Autism Spectrum Disorder.

We began the week with a new community services announcement shown on commercial television. Many thanks to Lisa and David Minchin for writing the information, helping with editing and appearing in the footage. Thank you also to people at Early Special Education at Campbell Street, Hobart and also the thoughtful camera crew.

Saturday, 10 May saw many families having rides on the miniature trains in conjunction with the Evandale Market. The Evandale Light Railway Society ran their trains free of charge for Autism Tasmania families and generously donated their revenue for the day to us. This is the second year that they have so and its great to receive such wonderful support.

During the week The Mercury ran articles on Autism Spectrum Disorder focussing on the impact that autism can have on a family. ABC Radio ran an interview on their afternoon Drive Show in the south of the State.

On Friday, 22 and Saturday, 23 May, Loiuise Uliana presented workshops in Launceston to both parents and professionals (see report on page 2). Unfortunately, Hobart's get-together was rained-out but thank you to those people who persevered and did attend!

A big thank you to all our sellers who braved the (mostly cold) weather to sell badges on Friday, 22 May - your help in spreading the message and raising funds is greatly appreciated.

Our next issue will be posted in September - if you have an article you want included, an experience to write about or a view to express, the deadline date for copy is the Friday, 28 August 1998

Annual General Meeting

11am, Saturday, 15 August 1998

Kings Meadows
Community Health Centre
Mc Hugh Street
Kings Meadows, Launceston

Please bring a plate of lunch to share

Guest Speaker: Mrs Kathy Gill
speaking about her role as the
Autism Consultant with DECCD

Nomination forms for candidates for election as office bearers and members of the Committee are included in this issue. The blank forms can be copied. Please follow the instructions on the form when lodging a nomination.

Young Autism Support Tasmania (YAST)

Recently, YAST held their inaugural General Meeting following incorporation. The following office bearers were elected,

President	Grace Talbot
Secretary	Rosemary Rush
Treasurer	Tracey Dillon

Congratulations to Grace, Rosemary and Tracey.

YAST is an organisation of supporting families teaching ABA. To find out more, ring Grace on 6229 7818

From strength to strength

The last week of first term was a rollercoaster ride of emotions for parents, staff and supporters of the Deloraine-based Giant Steps program. The anticipation and uncertainty of waiting was finally replaced by relief and euphoria that the Federal Government had decided to provide \$65,000 of emergency assistance.

"The decision is a great relief to everyone connected with the program", program manager, Mick Clark said.

"While not meeting the Centre's full needs, it will see us to the end of the 1998 school year", he confirmed.

Mr Clark said that everyone had been overwhelmed by the level of community support for the program and the amount of local and national media interest. National exposure on *A Current Affair* had resulted in calls, letters of support and donations from all over Australia.

"In times of crisis like this, it confirms the value of being part of a smaller community", he said. "Wherever we went, people asked about the money, when the decision would be, what our chances were. It's like being part of a big family".

Chairman, Penny Cromarty was equally delighted and said the result was a tribute to the effort and persistence of MLC, John Loone, the tireless work of Senator Brian Harradine and more recently, the help of Warwick Smith and his Tasmanian Federal parliamentary colleagues.

"Getting Giant Steps established has been 5 years of very hard work. The support that we've received from Tasmanian people and businesses has been a very important reason for our success", Mrs Cromarty said.

Importantly, the funds provide time for the Centre's Board and management to put in place the elements of the recovery plan that has been developed since late last year. Mrs Cromarty said that the Board doesn't see one single solution to its long-term sustainability but rather a combination of different elements.

"We don't believe that Federal or State Governments are meeting their social obligations to prop-

erly fund services for children with disabilities, especially Autism Spectrum Disorder", she said.

As part of the recovery plan, Giant Steps will continue to lobby governments to provide a more realistic and reliable contribution to the recurrent costs of providing its services but not depend on these results for survival.

Public and private fundraising will continue to play a very important part in Giant Steps financial development, in both the short and long-term. A comprehensive fundraising program is in place and already achieving much better results than in previous years.

Giant Steps will also be looking to expand its services, by offering parts of the program to families in different ways and by identifying other services which can be provided to people or organisations involved in the field.

"To provide quality services for the long-term, we need to become a robust and sustainable organisation. This means looking at both the costs of the existing program and opportunities to use our expertise in other ways to generate income", Mrs Cromarty said.

"We have a great group of staff and have learnt a lot over the last three years. The time is right to review how we do things and what we can learn from other people and programs in Australia and overseas", she added.

Mrs Cromarty said that considerable progress had been made in Tasmania since the early 1990s, with improved awareness and knowledge of autism, earlier diagnosis and the development of a choice of services for parents of younger children. However, a great deal of work remains.

"The services that we've got are fragile, not well funded or distributed across the State and overreliant on individual parents and volunteers", Mrs Cromarty said.

"We have a foundation to build on. With such a small, widely spread population, we feel a responsibility to work cooperatively and use resources wisely to develop the best choices and range of services for people whose lives are touched by someone with Autism Spectrum Disorder", she said.

Asperger Syndrome & Autism

On Friday, 27 March, along with a huge number of other professionals from all around the State, I attended the first of two seminars by the eminent Dr Tony Attwood. Furious writing of notes by the audience as he spoke, was indicative of the high quality of his presentation. Tony covered the characteristics of Autism and Asperger Disorder, medical disorders associated with Autism and pathways to diagnosis of Asperger Disorder.

The characteristics of Asperger Disorder that he highlighted include: an eagerness for aloneness, ignoring people, poor social interaction, abnormal eye contact, no effort to communicate using voice or words, lack of appropriate facial expressions and gestures, stereotyped vocal and voice utterances, echolalia or asocial speech, lack of initiative, poor activity, inappropriate relating to objects, resistance and frustration to change, stereotyped sensorimotor activity, bizarre posture and gait, auto-aggressiveness and self-injury, aggression towards others, soft anxiety signs such as giggling inappropriately, mood difficulties, disturbances of feeding behaviour, unstable attention and bizarre responses to auditory stimuli.

Tony also spoke about the autistic continuum, from aloof through passive to active but odd. He discussed the Australian scale for Asperger Disorder that he developed, which is an excellent tool for diagnosis. Tony placed a heavy emphasis on the importance of the explicit teaching of social skills and discussed the stages in developing these skills. He also discussed at length the emotions and exploration of the world through the senses.

On the following day, a large number of parents attended the second presentation. Tony again discussed the importance of social skills, communication and some strategies for dealing with these. A large portion of the day was dedicated to a question and answer session; the day concluded with a video, *Inside Out*, featuring the well known Donna Williams, sharing her personal perspectives on Autism.

Overall, Tony's presentation over the two days was thoroughly informative. Please contact Kathy Gill for more detailed information. Tony has written several books; his latest, *Aspergers Syndrome:*

A Guide for Parents & Professionals is available through Autism Tasmania.

Visual Communication Workshops

Louise Ulliana presented 2 days of workshops as part of our activities for national Autism Awareness Week. Louise is a speech pathologist and principal of Wetherill Park School in Sydney.

Workshops were presented to professional and parent groups, the focus in both being visual communication. The first part of the workshop defined visual communication, identified why we use visual approaches with people with autism, research involving people with autism and types of visual representation.

Louise supported her talk with a wide range of very practical displays. Each type of communication board, book or sequence was eye catching and simple enough to be replicated by anyone living or working with a person who has communication difficulties. Louise dealt with the requirements of both the visual aid and the person, the formats possible, construction and teaching hints.

Visual Sequences for Flexibility, Independence and Anticipation Skills was the second part. The last, Visual Behavioural Support Systems to Teach Self-Management, covered such aspects as dealing with planned change, the benefits of visual sequencing, communication-based intervention, supporting challenging behaviours, systematic desensitisation and writing social stories.

Those who attended were lavish in their praise of Louise, her presentation and the subject. Those who didn't attend missed a tremendously authoritative, practical and entertaining day.

Thanks must be extended to all those people who helped with the Tony Attwood and Louise Ulliana seminars. Organisation of these days requires a lot of work before the event as well as on the day.

The eye-catching displays in the foyer at the Tony Attwood seminar were the work of Penny Cromarty, Cheryl Scott and Ros Ward and provoked a lot of comment. Thanks also to Paula and Ron Barnes and Committee members of Autism Tasmania.

THE SIBLINGS

The following extract from "Autisma family affair" by Dr Joan M Curtis M.B., B.S., F.R.C.O.G., F.R.A.C.O.G and published by Mansfield Autistic Centre, Victoria, is reprinted by kind permission.

The brothers and sisters of an autistic child are in a difficult situation and often receive insufficient help. Of the vast literature on autism, very little deals with the problems of the siblings. Having an autistic brother or sister can be a devastating experience by which the individual is emotionally crippled. Alternatively, it can result in great personal growth and the development of an exceptionally mature and compassionate outlook. Much will depend on how the problem is handled. The attitude of the parents is the key, but doctors and teachers can help by drawing the parents' attention to the need which exists and guiding them to respond appropriately.

When the autistic child is young, the anxiety surrounding his condition, the visits to clinics and specialists, and the disturbance caused by the child's behaviour, may occupy the time and energies of the parents to the point where all normal family activities cease and the other children's needs are overlooked. Often no explanation is given, and the siblings may feel they are unloved or even blamed for the family difficulties. What is obvious to the parents- ie. that the handicapped child is a source of grief and worry, while the normal children are a source of joy and comfort - may be completely obscure to them. One warm-hearted little extrovert uncovered this problem for me by asking simply "Why do you love Jonathan more than me?" but many other children grieve silently and never receive the reassurance they need.

As the autistic child grows bigger, damage to the siblings' property, disruption of their activities, embarrassment of their friends, teasing at school, and sometimes physical injury by the autistic child are problems which must be dealt with fairly, sensibly and compassionately. It is not fair or sensible to allow the autistic child to tyrannise

over other members of the household. Part of his program will involve learning to respect other people and their property, but until he has learned, a few locked rooms and cupboards may be the practical solution.

There is no secrecy about autism and a clear and simple explanation to school friends will satisfy honest curiosity and help prevent teasing which is often fed by ignorance. Special efforts should be made by the parents to include friends of the siblings in family activities, such as a picnic, where they can observe the autistic child without having to be closely involved with him if they do not wish. Some useful allies can be recruited in this way.

Where the siblings are several years older than the autistic child they may voluntarily assume a parental role towards him. This can be very helpful, but it should not be allowed to interfere with the normal school and social life of the sibling.

As the autistic child's program proceeds, the life of the family will become more normal. Family outings will be more frequent and pleasurable. Tantrum behaviour in public will become under control. Respect for property and some sharing of domestic tasks will develop. Greater skills will lead to a more acceptable role for the child within the family. All these things will tend to make life easier for the siblings and they gain in confidence by having a role to play in helping to bring them about.

See page 11 for details of resources, references and recommended reading on sibling issues.

THE SIBLING EXPERIENCE OF DISABILITY

Brother/sister relationships are perhaps the most ambivalent of all human interactions, with extremes of emotion enhanced when one sibling has special needs. Research into sibling relationships where disability is involved has revealed a number of common themes. While each sibling is different and copes in his or her own way, it is likely that all will experience at least some of the concerns outlined below:

OVERIDENTIFICATION

Sometimes a sibling may worry that s/he may develop the same disorder as their brother or sister. This is influenced by severity and is more likely to occur in the case of mild disorders (Grossman, 1972). It is also more common in disorders that are less "visible", including epilepsy and milder forms of autism. Age also affects the occurrence of overidentification, and Miller (1974) suggests that a sibling is more at risk if their brother or sister with special needs is older.

Providing siblings with accurate information about relevant disorders is one way to reduce the risk of overidentification. It is crucial for adults to remember that not everything that seems obvious to them will be automatically taken on board by their children and honest, open discussion is the best choice.

EMBARRASSMENT

A child with special needs may be a source of acute embarrassment and unwanted attention for his/her siblings, especially in relation to mild disorders, or when the cause is not visible and/or manifests itself in the form of aberrant behaviours (for example, an autism spectrum disorder versus physical disability). Siblings sometimes worry that those looking at their brother or sister are also making judgements on themselves and their family as a whole (Helsel et al, 1978).

It is important to remember that children pass through normal stages of development where embarrassment is more easily felt (particularly ado-

lescence), and that this is usually transitory.

Devising strategies to avoid or minimise sibling embarrassment requires careful analysis of its cause to decide whether or not it is something that can be changed (such as addressing a difficult behaviour through a behaviour support program) or about which little can be done. In the latter case, children are especially helped by parents who acknowledge the embarrassment, encourage open discussion and do not discourage children from expressing their feelings.

GUILT

Siblings of children with special needs are more likely to experience guilt than those with normally developing brothers and sisters. This guilt can take a variety of forms:

- ◆ feeling of responsibility - a sibling may feel a disability was caused by their own thoughts or behaviour around the time of diagnosis and that their brother/sister would not have been punished if they had behaved differently
- ◆ survivor's guilt/guilt over abilities or health - while appreciating their own "normality", siblings may feel remorse that they are able to live life minus the struggles of their brother or sister, and may wish to be able to trade places
- ◆ guilt over typical sibling conflicts - "normal" siblings may be made to feel that they are not allowed to get angry, tease or argue with their brother or sister. Conflict, however, can be a positive step towards healthy social development and exposure to it within the home can better equip a child with special needs to deal with its resolution in the harsher outside world.
- ◆ guilt regarding caregiving - older siblings in particular may feel guilty about wanting to pursue independent lives, away from their less independent brother or sister shame - this mixture of guilt and embarrassment can have powerful and long-lasting effects. Shame has been found to be more prevalent in families with two children, where one has special needs and the other not (Dyson, 1989) and is less likely to occur in families who openly discuss disability.

ISOLATION, LONELINESS AND LOSS

It is understandable that parents may become pre-occupied with their child's diagnosis and needs, but this often results in other siblings feeling neglected and isolated from parental attention. Preoccupation is especially marked during periods of stress relating to the diagnosed child (for example, occurrence of seizures), when the emotional needs of siblings are at their highest.

Without open communication from parents, siblings can also feel isolated from information regarding their brother or sister's diagnosis/treatment and as such should be included in discussions as much as possible.

Sibling experiences parallel those of their parents in relation to the child with special needs and brothers and sisters, commonly feeling isolated from others in their situation, have the same need for peer support as their parents. Unfortunately there is less availability of sibling-specific support services in the community.

RESENTMENT

A sibling may feel that the child with special needs is receiving an unfair share of parental time and resources, and that they themselves are victims of unequal treatment and excessive demands. Young siblings in particular may lack the cognitive ability to place things in proper perspective and are more at risk of feeling unloved and unappreciated.

Resentment may also occur when a sibling perceives that parents have expectations that they will someday take on guardianship of their brother or sister, and this can take root from quite an early age.

INCREASED RESPONSIBILITIES

Research (such as Seligman, 1979) suggests that the amount of responsibility placed on a sibling in caring for a brother or sister with special needs has a major impact on that sibling's perception of and feelings towards their "special" sibling and parents, throughout the lifespan. It also has major implications for the development of anger, resentment, guilt and in some cases psychological diffi-

culties. Female siblings tend to shoulder more caregiving responsibilities (Grossman, 1972) and as such parents must be careful to share tasks equitably.

PRESSURE TO ACHIEVE

Some siblings feel that they must excel in areas such as academics, sports, music or behaviour to compensate for the different abilities of their brother or sister with special needs. While parents may be responsible for either consciously or

unconsciously raising their expectations of a normally-developing child, the sibling may also place pressure on him/herself. This need-to-achieve perception of normally developing siblings may be shame/guilt-driven and can become a source of resentment, anger and anxiety (Murphy, 1979) if left unnoticed and unmanaged by parents.

While the above discussion has focused on potential concerns for siblings of children with special needs, it cannot be stressed enough that children with disabilities also provide their siblings with many unique opportunities. In particular the special experiences of normally-developing siblings promote greater adjustment, maturity, responsibility, insight and tolerance than their peers (Simeonsson and McHale, 1981); have positive implications for self-esteem and social competence; can influence vocational choices and equip and encourage siblings to become effective disability advocates.

Rachel Evans is an experienced speech pathologist, currently working as a play and social communication specialist with Giant Steps Tasmania. Rachel has recently joined the Management Committee of Autism Tasmania.

(Reference: Meyer, Donald J and Vadasy, Patricia F Sibshops - Workshops for Siblings of Children with Special Needs. Paul H Brookes Publishing Co Inc, Baltimore, 1994.)

INFORMING SIBLINGS ABOUT DISABILITY

Like their parents, siblings of children with disabilities or special needs require ongoing information and reassurance regarding their brother or sister's diagnosis and its implications. Unlike their parents however, siblings lack life experience and mature understanding and are less able to access relevant information. All of this can contribute to misunderstandings about the special needs of their brother or sister.

With a diagnosis such as autism spectrum disorder, the need for information will continue across the lifespan. The best ways to address them will vary according to age; parents can help avoid misunderstandings by giving information in age-appropriate ways.

PRESCHOOLERS

In interpreting the world around them, preschoolers draw on both firsthand experience and imagined scenarios (since their real-life experience is limited). Being concrete thinkers, misunderstandings arise easily, in particular the experience of common illnesses (such as a cold) can manifest in beliefs that they have somehow caused their sibling's disability and/or may "catch" it themselves.

Clear, simple explanations about a child's disability can be understood by siblings as young as 3 years old, especially if that sibling has contact with other non-disabled children and therefore opportunities to recognise differences in ability. It can be helpful to explain a disability in relation to differences in behaviour or daily activities - for example, that "autism means that David goes to see someone to help him learn to talk".

SCHOOL-AGE CHILDREN

Children in this age group frequently have endless questions about their sibling's disability, as well as theories about its cause. These theories can give parents valuable insight into their child's beliefs, and in particular alert them to any responsibility or guilt the child may be feeling. A lack of questions may indicate feelings of resentment towards the child with a disability.

Questions of school-age children are often very specific and require honest, detailed answers both to satisfy their own curiosity and provide them with accurate information to pass on to classmates who regularly ask questions of their own.

ADOLESCENTS

Specific questions continue to be voiced by this age group, although are obviously more complex in nature. Adolescents require answers to questions but also strategies that help them deal with the acute embarrassment that is so common during this period.

It is important for parents to be aware that teenagers may continue to have misconceptions about their sibling's diagnosis. Also, not all teenagers feel comfortable asking questions and parents should not assume that this indicates a lack of interest but rather be sensitively proactive in their provision of information.

In addition to directly providing verbal/written information, it is important to encourage and assist adolescents to seek out information for themselves, thus facilitating a greater sense of ownership of their sibling's diagnosis and needs.

In summary, the manner in which parents disseminate information impacts heavily on the ability of siblings to adjust to their brother or sister's diagnosis. Misconceptions are best avoided by:

- ♦ **open and honest discussion** - preferably in frequent, small doses - rather than shielding from reality.
- ♦ **seeking out appropriate sources of information and support** - siblings do not have the same access to appropriate information as their parents as most support groups and written materials cater mainly for adult consumers.
- ♦ **including siblings in visits to service providers** - siblings are traditionally excluded from the information exchange associated with clinic visits, educational meetings and the like.

The need for service providers to develop a more family-centred orientation, particularly in relation to siblings needs, cannot be over-emphasised.

Rachel Evans

SIBLING NEEDS - HELPFUL INFORMATION FOR PARENTS

Reproduced with permission from The Centre for the Study of Autism, from an original article by Derenda Timmons Schubert, Ph.D., Western Psychological and Counseling Services, Beaverton, Oregon, USA 97005

Developmental considerations - what do you tell them?

Preschoolers

- ◆ Children of this age are unable to articulate their feelings about things, so they will likely show them through behaviours.
- ◆ They will be unable to understand the special needs of their sibling but will notice differences and try to teach their brother or sister.
- ◆ Children of this age are likely to enjoy their sibling because they have not learned to be judgmental and their feelings will likely be linked to normal sibling interactions.

School-age children

- ◆ These children start venturing out into the world and become acutely aware of the differences between people.
- ◆ They have the ability to understand a definition and explanation of their sibling's special needs, as long as it is explained in terms they can understand.
- ◆ Children at this age may worry that the disability is contagious or wonder if something is wrong with them also.
- ◆ They may experience guilt for having negative thoughts or feelings about their sibling, as well as for being the child who is not disabled.
- ◆ Some typical responses are to become overly helpful and well behaved or to become non-compliant to get their parent's attention.
- ◆ Throughout this age span, the children will have conflicting feelings about their sibling; this happens in sibling relationships that do not include a disability, too!

Adolescents

- ◆ Adolescents have the capability of understanding more elaborate explanations of the particular disability; they may ask detailed and provocative questions.
- ◆ The developmental task of adolescence is to begin discovering oneself outside the family. At the same time, conformity with a peer group is important. For children of this age having a sibling who is different, may be embarrassing in front of friends.
- ◆ They may feel torn between their desire for independence from the family and maintaining a special relationship with their sibling.
- ◆ They may resent the amount of responsibility and worry about their sibling's future.

What you can do!

Educate your children

- ◆ Provide information about how the condition is diagnosed, assessed and treated.
- ◆ Children need to know what the disability is and what to expect.
- ◆ Explain the strengths and weaknesses of the their sibling.
- ◆ Explain ways to help and interact.

Balance time spent with children

- ◆ Encourage the child to have activities unique to him or her.
- ◆ Have parental participation in activities outside the disability community.
- ◆ Recognise your child's strengths and accomplishments.

Open discussion

- ◆ Encourage open discussion within the family, where members' positive and negative feelings are expressed.
- ◆ Discuss ways to cope with stressful events such as peers, public reaction unexpected changes in family plans and extra home responsibility.

Sibling groups

- ◆ Participation in a group for siblings allows the children to meet others who are in the same circumstances.
- ◆ It provides children with a chance to discuss feelings which may be difficult to express in the family.

Warning signs

Depression

- ◆ Change in child's sleeping or eating habits.
- ◆ Sense of helplessness or hopelessness.
- ◆ Continuing sense of irritability.
- ◆ Mentions hurting self, (eg. "I wish I were dead")
- ◆ Difficulty making decisions or concentrating.
- ◆ Lack of pleasure in activities, social withdrawal or low self-esteem.

Anxiety

- ◆ Excessive worry.
- ◆ Increased energy level without a purpose.
- ◆ Tearful at the slightest frustration.
- ◆ Difficulty separating from parents.
- ◆ Changes in sleeping or eating habits.
- ◆ School phobia.
- ◆ Worry about health or well-being of family members.
- ◆ Somatic symptoms (eg. stomach aches, headaches)
- ◆ Perfectionism

Meyer, Donald J and Vadasy, Patricia F Sibshops - Workshops for Siblings of Children with Special Needs. Paul H Brookes Publishing Co Inc, Baltimore, 1994

This user-friendly manual describes the Sibshop program developed in the United States. Sibshops are workshops aimed at providing brothers and sisters of children with special needs opportunities to meet together in a relaxed, recreational atmosphere for the purpose of gaining peer support and education. It is stressed that while Sibshops may have a therapeutic effect for some participants, they are not intended as therapy (any children seemingly requiring extra support are referred on to outside agencies as appropriate) but rather to reinforce to siblings how well they are coping with the many difficulties that come with having a brother or sister with special needs.

The Sibshop program was originally devised to cater for 8 to 13 year old siblings of children with developmental disabilities, however has also been adapted for slightly older and younger children and those with siblings with a wider variety of special needs, including medical conditions (such as epilepsy), hearing and visual impairments and emotional/psychological disorders. Workshops have also been run for children having experienced the death of a family member. The Sibshop model caters for both urban and rural communities and incorporates cultural diversity.

The program format utilises games, activities and guest speakers to meet its goals of providing opportunities for siblings of children with special needs to:

- ◆ meet with one another and develop supportive peer relationships
- ◆ share common experiences and concerns with others in a similar situation
- ◆ learn coping strategies relating to commonly faced situations
- ◆ learn more about their sibling's diagnosis/special needs and how these impact on the special child's current and future life

Sibshops also aim to provide parents and professionals with opportunities to learn more about the

experiences and concerns of siblings of children with special needs.

Ideally Sibshops are run by a team of facilitators representing a range of support services, for example social workers, special education teachers/workers, psychologists and other health professionals in addition to adult siblings of children with special needs.

Sibshops are typically and most effectively run on a regular basis (for example monthly or bimonthly as a weekend program) to encourage attendance by a consistent participant group and so foster long-term friendships, but are also valuable offered in isolation (such as alongside family conferences). It is suggested that attendance of a dozen siblings works best, however the authors have run workshops for 5 up to 45 children depending on need and availability of resources through sponsorship by community organisations.

The Sibshops manual takes the user through every stage involved in organising and running a single or series of sibling workshops. It provides a detailed guide to the emotional and informational needs of different aged siblings of children with special needs (discussed in a separate article in this newsletter) and a plethora of recreational and discussion activities to address them. Proformas for letters, activity/feedback sheets, posters, etc are also provided. Additional chapters are devoted to conducting workshops to educate parents and professionals about sibling issues, and for adult siblings of people with disabilities.

Sibshops - Workshops for Siblings of Children with Special Needs highlights the need for a family centred approach to disability and makes a comprehensive and important contribution to literature in this field. In particular it alerts the reader to the special and often overlooked needs of siblings and the importance of sibling support provision. The Sibshop program has enjoyed great success across the United States and Canada in providing support, information and enjoyment to siblings of children with special needs.

(Sibshops - Workshops for Siblings of Children with Special Needs is available from Open Leaves Bookshop for \$58, plus Postage & Handling)

Rachel Evans

Some references and recommended reading on sibling issues

- Armenta, C. (198?). *Russell is Extra Special - A Book About Autism for Children (AT Library)*
- Bodenheimer, C. (1979). *Everybody is a Person: A Book for Brothers and Sisters of Autistic Kids*, Syracuse, NY: Jowonio - The Learning Place (suitable for early to middle high school level)
- Davies, J. (199?). *Children with Autism: A booklet for brothers and sisters*, Child Development Research Unit, University of Nottingham (AT Library)
- Gold, P. (1975). *Please Don't Say Hello*, New York: Human Services (primary to early high school)
- Harris, S. (1994). *Siblings Of Children With Autism*, Bethesda, Maryland: Woodbine House (parents & professionals)
- Howlin, P & Rutter, M. (199?). *The Alleviation of Family Problems*, The National Autistic Society (AT Library)
- Lobato, D. (1990). *Brothers, Sisters and Special Needs*, Baltimore, Maryland: Paul Brookes (parents & professionals)
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- Powers, M. (1989). *Children With Autism: A Parent's Guide*, New York: Woodbine House (parents & professionals)

also

Sibling Information Network
Department of Educational Psychology
Box U-64
University of Connecticut
Storrs, CT 06268 USA

If you know of other resources that may be helpful with sibling issues, please let us know and we can include the details in a subsequent issue or purchase the resource for our regional libraries.

In a reader's recent letter to the editor, published in our March edition, regarding side effects from SSRI's, in particular the drug, Prozac (fluoxetine) we found the following article in

Autism Research Review International: Volume 11, Number 1, 1997: Biomedical Update Pg 4.

More concerns about movement disorders caused by SSRIs

A relatively new class of drugs called selective serotonin reuptake inhibitors (SSRIs) is gaining popularity for the treatment of autistic aggression and self-injury (see ARRI 10/4). New reports, however, suggest that the SSRIs - while apparently safer than older neuroleptics such as Haldol - can occasionally cause movement disorders, particularly when combined with other medications.

ARRI 10/4 summarized a report by Steven Dubovsky and Marshall Thomas, who found that Prozac (fluoxetine) can sometimes cause tardive dyskinesia, a neurological disorder resulting in

involuntary muscle movements such as chewing, swallowing, and lip smacking. Similarly, a new literature review by Raphael Leo found a number of reports associating Prozac and other SSRIs with tardive dyskinesia. In addition, the researchers report that the drugs can cause other serious movement disorders including:

- akathisia (motor restlessness that causes quivering, anxiety and an inability to sit still);
- dystonia (including symptoms such as muscle spasms, jaw tightness or twisting of the neck);
- parkinsonism symptoms including rigidity, tremor, gait disturbances, and a mask-like appearance.

Leo used MEDLINE searches to identify physicians reports of movement disorders associated with SSRIs. He found 71 cases reported, with akathisia being the most common condition.

Leo notes that the literature of Eli Lilly and Company, which manufactures Prozac, reports "375 cases of akathisia, 218 cases of dystonia, and 76 cases of tardive dyskinesia" associated with the drug as of December 1995, and that the World

Health Organization has received 438 reports of movement disorders associated with Prozac. "Although these side effects are infrequent," he says, "clinicians should be alert to the possibility of their occurrence."

Leo's own research suggests that individuals most at risk for SSRI-linked movement disorders include older patients, those with Parkinson's disease, and those taking multiple drugs. Although side effects are most often reported with Prozac, he says, it is not clear if this is due to the drug's popularity or to pharmacological differences among the SSRIs.

"Movement disorders associated with the serotonin selective reuptake inhibitors," Raphael J. Leo; Journal of Clinical Psychiatry, 57, 10, October 1996, pp 449-454." Address: Raphael J Leo, Department of Psychiatry, State University of New York at Buffalo, Erie County Medical Centre, 462 Grider St, Buffalo, NY 14215

Asperger Support Group

We missed you at the last meeting of the Aspergers Support Group. We hope you are able to come to the next meeting which will be held at the home of,

Jan Mahoney
4 Norman Circle
Glenorchy
telephone 6272 1049

If you are able, please bring a small plate of supper. We hope to watch a short video of Temple Grandin talking about Asperger's Syndrome.

If you want more information about our group or have any questions, please contact:

Rosanne Lay
54 Waverley Street
Bellerive TAS 7018
telephone 6244 2540

An Asperger Support group is being established in Launceston. We will have more information in our next newsletter.