



## The following Article was presented to the AGM by the President

Welcome to the 13th Annual General Meeting of Autism Tasmania. It has been another busy although at times frustrating year as we work towards achieving our goals. Certainly there have been some highlights and of particular importance is that the organisation is in a much stronger financial position than at this time last year. However, long term funding is not secure and this will continue to be a focus for the new committee. Late in 2004, we were successful in applying for and receiving several grants to develop our services to members and the wider autism community. Through the generosity of Tasmanian grant making bodies we were delighted to receive grants for \$1,500 from the Launceston Mayor's Ball, \$17,560 (excluding GST) from the Tasmanian Community Fund and \$9,715 (excluding GST) from Anglicare, under the Communities for Children project. Additional funds of approximately \$6,500 from the Communities for Children program have also been allocated to Autism Tasmania for the coming financial year.

The Family Support Service led by Family Support Co-ordinator Rose Clark, has continued throughout 2005 with assistance from the above grants. Rose continues to be the main contact for people seeking information about Autism Spectrum Disorder and options available to people with the disorder and their families. Rose works tirelessly with support groups throughout the state, helping to provide guest speakers or social get togethers as required by members. We understand the value of Rose attending all support group activities, however it is our vision that in the long term support groups will be empowered to assist each other on a greater basis and exist with occasional visits from the Family Support Co-

ordinator. We have seen the beginnings of such autonomy when late in 2004, the East Coast group conducted a very successful autism conference "Unlocking the doors".

The second Autism Tasmania state conference was held in Hobart earlier this year with an attendance of 300 delegates. The conference was conducted with the assistance of the Commonwealth Respite for Carers Program. With Dr Tony Attwood as a keynote speaker, we always believed we would attract a large audience despite the short time frame available to us for registrations, especially given the

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Easter break just prior to the conference. However, we were overwhelmed by the response which certainly tested our voluntary capacity to the limits. The conference committee chaired by Penny Cromarty and assisted by Mary Brake, Robyn Lake, Rose Clark and Sue Brown, who volunteered their services, organised an outstanding conference. Due to the unavailability of Wrest Point, the conference was held at the University in Hobart and there were both positives and negatives associated with this venue. Unfortunately the traditional arrangements for CRC funding have ceased and been replaced by a call for tenders to physically provide respite care, which is beyond our capacity.

Our tenuous financial position this time last year saw Autism Tasmania "grab" the opportunity to be involved with National Foods and participate in the Launceston and Hobart Shows and Agfest. Under the guidance of Mick Clark, we sold milk, other dairy products, National foods show bags and supplied many stands around these venues with their catering requirements. With assistance from a large number of volunteers, many of whom had no association with Autism Tasmania, we manned stalls and vans at these events and provided valuable cash flow to our organisation. As I write this report however, National Foods will not be participating in the Launceston Show in 2005 and perhaps only on a limited basis at the Hobart Show. It is unclear what opportunity there may be for involvement by Autism Tasmania in the future.

Cheryl Scott has again edited the newsletter and bulletins this year and I thank her for her efforts. Producing a quality newsletter has proved a challenge, as many people now have access to the internet and the wealth of information available. As a result, in some issues we have chosen to focus on local content, and to keep members informed about events occurring within the state. We welcome input from members as to the future direction of the newsletter.

The committee has continued to meet monthly using the Telehealth facilities and this has proved very successful with short, frequent meetings. However, we recognise that it is important that we meet face to face and this year held a full day meeting at Campbell Town in July. At this meeting we identified the things we were proud of, but also the many issues we felt we could do better. One of these is National Autism Awareness Week, which unfortunately this year passed with a whimper as it followed closely on the heels of the conference and Agfest. My thanks however go to ABIT (Autism Behavioural Intervention Tas - led by Rosemary

Rush) and in particular Nigel Geard who co-ordinated Button Day in the south of the state. Rose Clark took on the job of co-ordinating the selling of buttons in the north and north west and some good results were achieved, particularly in the south.

Also on our agenda is the library, website and our image, in particular the logo. It is generally felt that it's time to get rid of the sad face. Membership remains at a healthy level and is now being maintained by Louise Davies. Louise has kindly taken on this role after some difficulties earlier this year when renewals were not sent out on time. It is our plan to put effective systems in place to develop these activities. For example we have people who are willing to "run" the library, but are yet to find anyone who can develop and establish an appropriate computer system to manage the flow of books.

I would like to thank those people who have assisted our organisation throughout the year. Thank you to Neil Gardner who took on the role of Treasurer earlier this year in difficult circumstances and to David Savill and Karina Johnstone at Giant Steps who have provided some administrative support. Thank you also to Geraldine Robertson our webmaster, who is based in Rosebery. Geraldine continues to work towards developing and updating the website. Thank you also to Sue Brown, Tasmania's nominee on the Autism Council of Australia's professional committee, who also regularly attends committee meetings and Louise Davies for taking on the management of the membership.

Thank you to Rose Clark for her commitment and efforts throughout the year as Family Support Co-ordinator. Few people would be prepared to travel throughout the state, often at night, the way Rose does. Autism Tasmania is managed on a voluntary basis and it continues to be a challenge to meet our committee obligations and manage our own family and work commitments effectively. Thank you to committee members, Penny Cromarty, Mick Clark (also Tasmania's representative on the Autism Council of Australia and President of this body), Neil Gardner, Cheryl Scott, Rosemary Rush, Andrew Davies, Peter Hatters and Debb Manser for their outstanding efforts over the past twelve months and to their families for their support.

Finally I would like to thank to Mark and Kathryn Ward for their assistance and support throughout the year and to Michael who continues to motivate me to improve services for people with Autism Spectrum Disorder in Tasmania.

Ros Ward (Mrs) President

## National Autism Forum: Keynote Address—by Prof. Margot Prior *University of Melbourne and Royal Children's Hospital, Melbourne*

*This article was taken from Prof Margot Prior's Keynote Address at the National Autism Forum held at Parliament House in June 2005*

Professor Prior acknowledged the level of awareness represented at the forum regarding Autism Spectrum Disorders (ASD), and that her address would provide an overview of the key issues of concern. The profile of autism as a national interest issue has generated considerable research and a solid knowledge base to guide clinical and educational practice.

Professor Prior's presentation concentrated on the following issues and challenges:

**Diagnosis and Classification of Autism Spectrum Disorders** Autism is now seen as relatively common. The increase in the presence of ASD can be attributed to the following factors:

- Changes in diagnostic practices
- Greater awareness of autism (both public and professional knowledge)
- Early diagnosis (previously around 5 years of age and now at 2 years of age)
- Services and administrative decision making influences i.e. willingness to make a

diagnosis that will lead to a discernable service

- Different methods used in epidemiological studies
- Effects of research into causes of autism together with enhanced media publicity.

### **Increased Prevalence of Autism**

A United Kingdom research project undertaken between 1988 and 2001 reported a ten fold increase in diagnosis of autism. There is general agreement that more children in Australia are presenting for assessment and requiring services and family support. Attention to the chronic shortage of appropriate education and care for those affected is critical.

### **Causes of Autism**

There is still considerable debate surrounding the aetiology of autism spectrum disorders and although

there has been extensive research no definitive answer exists. There are multiple interacting factors and no specific genes have been reliably identified. Claims about the influence of toxic factors have generally not withstood careful scrutiny but there is a need to continue to research the impact of environmental influences.

### **Asperger's Syndrome**

Asperger's Syndrome is at the high functioning end of the spectrum of autism. Diagnosis of this syndrome is occurring in more intellectually able children with well developed language skills and less severe social impairments. Asperger's Syndrome and high functioning autism are similar and should not to be separated given recent research in favour of the spectrum or continuum concept of autism. In addition there is no evidence in the social communication or neuro-cognitive domains to separate these children diagnostically. Many children in schools who were previously not understood and seen as socially isolated and eccentric are now being captured in the recognition of this syndrome.

### **Challenges**

The following were outlined as challenges for children with autism spectrum disorders:

- Learning difficulties
- Particular problems with planning, organisation and attention
- Preoccupation and obsession issues
- Elevated levels of anxiety
- Problems relating to teachers
- Peer and social acceptance
- Unacceptable behaviours
- to bullying
- Experiencing and coping with stress

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### Treatment for Autism Spectrum Disorders

Current thinking on the treatment for autism spectrum disorders is as follows:

- With improving outcomes there is greater optimism that something can be done to enhance the development of children whose prognosis has always appeared to be poor
- Institution of earlier intervention is better for the family and the child
- The increase in expectations and expertise in teaching methodology, including new teaching and training techniques, is now well developed
- Recognition of the critical importance of parental commitment and involvement, whilst acknowledging this increases the burden on parents.

### Applied Behaviour Analysis (ABA)

Applied behaviour analysis is surrounded with variable evidence and controversies and does not suit all children. While applied behaviour analysis can achieve very good outcomes, it is not the only approach. Those children with initial higher levels of social and communication skills are likely to do better regardless

of the kind of intervention provided. Other systems need further evaluation. Government support for these services remains inadequate for such high needs children and their families. While applied behaviour analysis is seen as expensive, in comparison to other medical treatments for small groups of particular disorders, the relative cost is not high.

The following factors are critical for applied behaviour analysis to work well:

- high intensity of application and persistent and consistent intervention is required
- application at an early age is better than later
- requires many hours per week over a long period of time with high levels of family commitment
- Well trained therapists are critical

During discussion following Professor Prior's presentation, the point was made that were autism spectrum disorders considered a clinical disorder or disease, the service levels and access to services would be much higher. That autism spectrum disorders falls between an educational disability and health classification is one of the key difficulties in securing more resources and in providing coordinated services.

## Putting the Care back into Care-Giving: Some Suggestions from Parents by Michelle Rowbotham, PhD Candidate, University of Queensland

My research interest lies in the study of stress and coping processes, particularly the ways in which these processes change over time. I am currently seeking to understand how parents of adult children with intellectual disabilities cope with care-giving stress, a topic close to my heart, having grown up with my half-brother, whose intellectual disability resulted from meningitis contracted during his infancy.

One of the advantages of studying care-giving behaviour is that it is something with which everyone is familiar: all of us have been cared for by someone at sometime during our lives and many of us now care for our own children, partners or parents. Through this research, I have had the opportunity of speaking with many parents, in both urban and rural settings, some of whom have

been generous enough to share the ups and downs of their lives with me over a period of months. During these discussions, I have learnt that caring for an adult child with intellectual disabilities forges a unique bond between the adult child and their parents, as noted by Mother IOa, (2004), "The whole of your life is surrounded by the person you care for. They are more important than you are and you accommodate their needs more than your own: it's easier that way". However, I have also discovered that it is precisely this over-familiarity of experience that has contributed to discrepancies between the ways in which parents define care-giving and the ways they believe it is defined by non-caregivers. One example of this pertains to the

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notion that care-giving largely encompasses the amount of time taken to perform personal care tasks, as evidenced in the requirement for the provision of such details in the completion of mandatory government documentation. Another example is the perception of care-giving as an onerous task with limited positive benefits, a theoretical perspective that has given rise to a substantial volume of research (Anderegg, Vergason, & Smith, 1992; Bruce, Schultz, Smyrios, & Schultz, 1994; Davis, 1987; Lustig, 1996, 1997, 1999, 2002; Olshansky, 1962; Zuzich, 1980). Conclusions drawn from this research also tend to conceptualise disability per se as the primary cause of stress to care-givers, instead of considering the contributions of other potential sources of stress, such as negative life events (e.g., death of a loved one) and chronic role strains (e.g., daily hassles, such as being late for work) (Pearlin, 1999; DeLongis, Folkman, & Lazarus, 1988).

This leads to the question of whether the gap between the familial and professional/service provision notions of what care-giving is can be satisfactorily bridged. One possible way of doing this is via a more complete understanding of what care-giving actually entails. In relation to the issue of care-giving being tantamount to the performance of personal care tasks, parents confirm that these tasks do encompass a significant proportion of their time, as stated by Mother 9a (2004): "24-hour monitoring is daunting, depressing and a huge responsibility. I am always responsible for my child's care". It is also well-documented in research that care-giving can be difficult in specific circumstances, such as caring for an adult with challenging behaviour, and balancing care-giving and employment commitments (Brubaker & Brubaker, 1993; Einam & Cuskelly, 2002; Pruchno, Patrick, & Burant, 1995; Shearn, 1998; Shearn & Todd, 1997, 2000; Smith, 1996; Ungerson, 1987). Some parents also remarked that coping with care-giving over a substantial period of time may also convey the appearance that they are able to continue managing independently for the foreseeable future. However, this perception may pose a particular danger, as crises can emerge quite unexpectedly, making it difficult to quickly marshal supports to contain them.

However, following on from this point and in consideration of the second issue pertaining to a tendency to emphasise the negative aspects of care-giving, more

recent research has found that care-givers also report significant satisfactions, such as better morale and knowing that they provide the best-quality care for their son or daughter (Freedman, Krauss, & Seltzer, 1997; Grant, 1989, 2001; Heller, Miller, & Factor, 1997, Nolan, Davies, & Grant, 2001a, 2001b; Nolan, Grant, & Keady, 1996; Seltzer & Krauss, 1989; Tobin, 1996; Todd & Shearn, 1996; Walker, Pratt, & Oppy, 1992). Parents have also identified other benefits, such as the company and support that they receive from their adult children with intellectual disabilities (Smith, Tobin, & Fulimer, 1995), and also from other family members and friends (Freedman, Krauss, & Seltzer, 1997; Grant, 1989; Heller & Factor, 1991).

Parents in the present study have also shared similar perceptions, as one mother remarked, "Care-giving encompasses much more than task performance; it is an expression of love for the person cared-for" (Mother 1a, 2004). Considered in this light, care-giving cannot be reduced to distinct elements that are easily quantified. Satisfactions may also extend to the emotional relationship between the parents, as remarked upon by Father 8b (2004), "Coping with crises has enriched our relationship by increasing our understanding of each other". These feelings, in turn, are constantly changing, and can also reflect an element of ambivalence. For example, as another mother noted "Caring is like living on the edge of a cliff you don't know if you're going to take the wrong step... sometimes you want to" (Mother 10a 2004)". Thus, while strained when care-giving is difficult, but bolstered when it is not, these emotional ties provide the energy by which the care-giving relationship is sustained over time. In view of these parents' perceptions and recent research exploring both care-giving costs and satisfaction's, a more accurate conceptualisation of care-giving can be proposed; one in which it is characterised as a symbiosis between the unique care-giving needs of the adult cared-for, the stressful circumstances facing the family at a given point in time and the satisfactions care-givers derive from their role. Closest to the hearts of parents about the process of care-giving is what the word 'care' means to them: it not only embodies objective elements, such as task performance, but also the most important subjective element of all: deep and lasting love.

(References available from author on request)

**Reprinted from Autism Victoria**

## Visual of the month

Reprinted from Autism Ass of Western Australia, August 2005 reprinted with permission

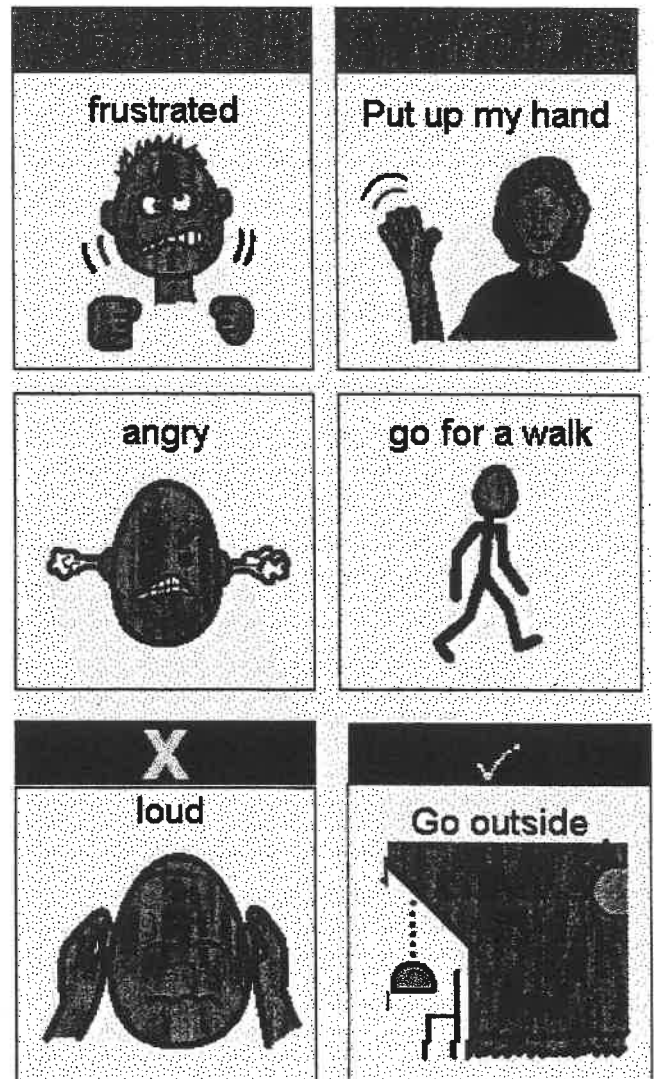
When we present seminars on challenging behaviour, people often ask questions about how to manage the situation when their students, clients or family members have meltdowns". Obviously there are many reasons for these stressful situations, but there are two common issues that are often involved. Firstly, when a problem arises the person with autism may not know what to do, Secondly, even when they have been taught what to do, they may not be able to remember the solution once they become distressed.

By having access to visual supports, in these situations, it is more likely that the person will be able to quickly and easily identify the solution to the problem, even when they are quite distressed. Given visual guidance, we can avoid overloading the person with verbal input, which, as we know, can be overwhelming to someone who is already upset. Visual supports can be adapted to meet the needs of people at a variety of different levels. It will not always be necessary to include words with pictures; this will depend, of course, on the person's ability. Many recent books on autism, including books reviewed in Autism News (WA) recently, describe ways of using visual communication, especially for when the person is distressed. The ideas presented here are adaptations of supports illustrated in texts by Susan Dodd and also Linda A. Hodgson (see below).

Of course, as with any other visual support, the individual must be taught what it means how to use it. They need to be taught to recognise the problem, and to know how to carry out the solution side of the "equation". If the solution is "listen to music", for example then the person must know where to access a CD player and CDs and how to play them. And, of course, this teaching should be carried out when the person is calm and things are going well, not when they are distressed. Finally, it is not possible, or desirable to put on such a chart every problem the person might encounter. Only a small number of commonly occurring problems should be included. In some cases it would be preferable to provide the

person with just one problem / solution visual support, especially if the person frequently has difficulty with a particular issue eg noise, and might be unable to pick out the relevant cue from a number of pictures.

Two of the many works, currently available, that illustrate the use of visual supports : Susan Dodd, Understanding Autism. Sydney; Elsevier Australia, 2005; Linda A Hodgson, Solving Behaviour Problems in Autism: Improving Communication with Visual Strategies. Michigan; Quirk Roberts, 1999



## Autism Council of Australia—Report from Mick Clark

A very brief update from the Adelaide Board meeting on 21 & 22 October 2005. In addition to key points summarised here, considerable work was done to define the needs & expectations of key stakeholders and simplify the operations of the ACA.

After persistent follow-up by A4's Bob Buckley, the Dept for Health & Aging finally provided the written outcomes to the National Autism Forum held in June. A4 and the ACA are presenting a joint set of autism priorities that can be acted upon by the Dept for Health & Aging, in response to the invitation by Christopher Pyne, Secretary to the Minister for Health [Tony Abbott]. Over the next few weeks and months both groups will be working together to pursue actions for autism through the key Australian Government Departments of Health, Education, Employment and Family & Community Services.

Securing funding for a national secretariat remains an imperative for the ACA, with the active help of A4. We believe the Australian Government should significantly fund a strong national and effective voice, without relying solely on the goodwill of interested and passionate individuals to represent the interests of people with an ASD, their families and carers.

All ACA directors are volunteers and it has no paid staff. To overcome this serious limitation in the short-term, the ACA has decided to commit much of its own limited money to fund a part-time project or executive officer for 2006. With generous assistance from Aspect [formerly the Autism Association of NSW], the person will work from their offices in Forestville, Sydney. Aspect staff will also be helping over the next few months with changes to the ACA website.

History has been made with the Northern Territory's Autism NT formally joining the Council. Their nominee director is previous long-time president & inaugural part-time executive officer, Alison Bird. All Australian states and territories are now represented on the Council.

New WA Autism Association nominee director, Val McElvey also attended her first Board meeting, following the resignation of long-time director, Joan McKenna Kerr. Val is an experienced ASD educational consultant with the Catholic Education Office.

Experienced special educator, Pam Young is NT's nominee on the ACA's Professional Committee. Also joining the Professional Committee are respected clinicians Dr Lawrie Bartak & Professor Bruce Tonge.

The Professional Committee has decided on the recipients for the 2006 Apex Trust for Autism/ACA Research Grants and a formal announcement will be made in November. While the available amounts are small, they do provide an important contribution and value the long association with Apex in Australia.

Professional Committee Chair, Dr Verity Bottroff is actively involved with the newly developing National Autism Research Alliance, championed by Deb Kean of the University of Queensland. While still in its formative stage, a nationally focused autism research alliance offers some great opportunities.

The ACA AGM will be held by teleconference on Friday, 25 November. The Board will meet again face-to-face in Albury in March, with a significant amount of time devoted to developing the collaborative relationship with A4.

### Tasmanian Government Concessions

A useful booklet of concessions for Tasmanians has been produced for 2005 and 2006 and is available from Service Tasmania.

- It is a simply laid out and easy-to-follow guide to concessions for:
- Motor vehicle and Driver's Licence
- Travel and transport
- Recreation and Leisure
- Community Services and Health
- Energy
- Education and Lifelong learning
- Financial and Property transactions
- Housing, accommodation and land
- Commonwealth Concession cards

## Picture Exchange Communication System - PECS®

The Myths and Misconceptions surrounding the Picture Exchange Communication by Amanda Reed  
Reprinted from Autism Victoria Spectrum Vol 1 no 2 2005

*You've heard about PECS, but do you really know what it is?*

Over the past ten years or so, PECS has become an acronym that is well recognised in the field of autism intervention. While many people have heard of PECS, though, there are a lot of myths and misconceptions about what the Picture Exchange Communication System (PECS®) really is. Outlined below are some of the most common myths.

*If we're using pictures of any kind, we're using PECS.*

PECS does use pictures, but it is a specific protocol for teaching expressive use of pictures for an individual to communicate wants and needs, and to comment about the world. The protocol involves six distinct phases of teaching, as well as strategies for introducing attributes (e.g. colour and size) into the individual's language. It combines knowledge from the fields of applied behaviour analysis and speech-language pathology to produce an effective and efficient method for teaching functional communication.

The teaching protocol was developed by Andy Bondy PhD, and Lori Frost SLP/CCC in 1985 and is now described, in its most up-to-date version, in the Picture Exchange Communication System Training Manual – 2<sup>nd</sup> Edition Edition (Bondy & Frost, 2002). This training manual is recognised by professionals in the fields of communication and behaviour analysis as an effective and practical guide to one of the most innovative systems available.

*We're using a visual schedule, so we're using PECS.*

PECS is an expressive communication system for the individual with severe communication impairment. Visual schedules are about receptive understanding. The Pyramid Approach to Education, of which PECS is a part, will make use of visual schedules, but they are not PECS per se.

*PECS is only for people who don't speak at all.*

PECS can provide a very effective functional communication system to individuals with no verbal communication, but it can also teach important skills to those who talk. The PECS protocol emphasises

teaching a person to approach others to initiate a communication interaction. Some people may talk, but don't understand that need for a social approach – they may talk to an empty room or to the fridge. These individuals may be able to learn about the social approach through PECS. Other people may talk, but will only do so if asked a question or told to use their words. These individuals may be able to learn about spontaneous, self-initiated communication through PECS. PECS can be an alternative communication system for those who don't speak or an augmentative communication system for those who do.

*PECS is only for young children.*

PECS has been used around the world with people aged from 14 months to 85 years. While the learning 56 process may be different for people at different ages or with different types of communication impairment, PECS can be an effective functional communication system right across the age range.

*PECS just teaches people to request.*

Requesting is the first skill taught in PECS, but the protocol's final phase focuses on teaching commenting (e.g. I see, I hear, I smell). PECS is not about a person just getting his/her needs and desires met, but about communicating with other people in his/her world.

If a person asks for something using PECS, we have to honour the request, and that will just produce a "spoilt brat".

The PECS protocol involves honouring every request during Phases I and II. This is the time when the person learning PECS is developing his/her trust in the communication system. If we start saying "No" too early, the person learning PECS may give up trying to communicate, because his/her experience is that it doesn't always work. Once the individual has mastered Phase II of PECS, we can be confident that s/he is a persistent communicator, and it then becomes appropriate to teach the concept that a person can ask for what s/he wants, but the answer will sometimes be "No".

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*If we use PECS, the person using the system won't learn to speak.*

As with any other alternative communication system, the use of PECS will increase the likelihood that a person will become a verbal communicator. Research has been carried out looking at the emergence of speech in PECS users, and the results indicate that speech may well be an outcome of PECS. What we also know, though, is that even if a person doesn't start to speak with PECS, that person will have an effective way of communicating with lots of different people in his/her world.

*PECS is only for people with autism.*

PECS was developed at the Delaware Autism Program in the United States and did therefore have its origins in the field of autism intervention. What has been discovered over the 20 years since the inception of PECS, though, is that it can serve as an effective communication system for a range of individuals with communication impairment. PECS is being used with individuals with autism, Down syndrome, Cri-du-Chat, Angelman's syndrome, developmental delay, language disorder, developmental verbal dyspraxia, head injury ... and the list goes on.

*In summary...*

The Picture Exchange Communication System (PECS©, Bondy & Frost, 2002) is a unique augmentative/alternative communication training protocol that has received worldwide recognition for focusing on the initiation component of communication. PECS does not require complex or expensive materials. It was created with educators, resident care providers and families in mind, and so is readily used in a variety of settings. The system has been successful with individuals who have a wide array of communicative, cognitive and physical difficulties. Training in the Picture Exchange Communication System is available through Pyramid Educational Consultants, a worldwide group of companies headed by Andy Bondy and Lori Frost. Our Pyramid consultants work closely as a team with Dr. Bondy and Ms. Frost to maintain their expertise and to update any PECS protocol modifications that are made.

If you would like to know more about Pyramid Educational Consultants or PECS, go to [www.pecsaustralia.com](http://www.pecsaustralia.com) or call (08) 8240 3811.

## Trampolines R Us—Autism Tasmania; local agent

Christmas is coming and here is the safest & easiest present you'll ever buy – and support Autism Tasmania at the same time. Tell your family & friends!

Autism Tasmania has jumped into a sponsorship agreement with Springfree Trampoline Aust Pty Ltd. We receive a donation of \$100 or \$200, depending on the size of each trampoline sold to individuals, or a special donation for specially priced school purchases.

Springfree is the safe trampoline – a totally new concept in design, removing all risk so kids can play & exercise safely. SpringFree has no dangerous springs or frame at the jumping surface, instead using flexible fibre glass rods clicking into a soft edge to provide bounce. Its FlexiNet enclosure eliminates ground contact without using rigid

metal poles and redirects jumpers back into the centre of the trampoline, with no risk of getting caught or hitting any enclosed poles.

SpringFree trampolines are featured on ABC TVs Active Kidz and you can see it on Better Homes & Gardens on Southern Cross Television at 7.30pm, Friday, 18 November 2005. Better still, click onto their website at [www.springfreetrampoline.com.au](http://www.springfreetrampoline.com.au) Call Mick Clark on 0417 354 157 or 6423 1086 for more information & to place your order.

## What makes Chris laugh?- A personal view from his mother by Cheryl Scott

Up until recently, I would have said that my son Chris' sense of humour was limited to responding to pleasant or exciting sensations. However this has changed so much in recent months, that his teachers have started to report instances of random acts of humour!

When he was little, one of the first things I remember him laughing at, was something he saw while looking out of the window of a fast moving car. The late afternoon sun was behind a long avenue of trees and the light flickered as we drove. I remember wondering what was so hysterically funny about trees whizzing by – and in retrospect, maybe this was an early clue to his Autism. He was in fact 'stimming' on the strobe effect – but it obviously delighted him and he giggled infectiously in his toddler seat.

As a little fellow, I caught him one day with a feather in his hand, lifting his own shirt and tickling his own bare tummy! There he was, having the best time and giggling fit to burst. More recently, I have seen him tickling his own feet. Try it yourself! I defy anyone to successfully tickle himself!

Chris used to laugh if someone was expressing anger in a physical way. It was not uncommon for him to laugh uproariously at a parent, who he could see going quite red, yelling and waving arms around. I'm sure he thought it was all a performance for his benefit – all that colour and movement! Unfortunately, this usually did little to defuse the already heated situation!

A few years later, at a time when he and his brother still shared a nightly bath, I was teasing Nick during the bath. Nick was over-reacting as usual and I turned to Chris and commented, "He's silly, isn't he?", while indicating Nick's reaction. Chris's own reaction was to immediately reach over to Nick, give him a playful cuff on the shoulder as if to say, 'Yes!. you duffer!'

Even though Chris is a happy fellow, and usually enjoys sensations he finds pleasant or exciting, I find it hard to think of many other instances of actual humour from that time until this year.

He has recently turned 17 and I believe his awareness of humour has risen sharply and I was reminded of this only a few weeks ago

Chris caught me watching him leafing through a book. He immediately raised his hand to shield his eyes from my gaze. I did not look away and I saw him cautiously peek out between his fingers at me. He saw me watching him watch

me, and a very sheepish expression crossed his face! He knew he'd been caught out – and he laughed with me! I have never seen such a self-aware action from him before or since!

In second term, we started to see him use language in his humour. He uses his Light writer for this, as his oral speech is still very poor and this allows him to write in sentences—and for the machine to speak aloud those sentences.

I've been told that he called his teachers 'a pack of ratbags' and then laughed and laughed..... I don't think anyone's feelings were hurt, thankfully.

On another occasion, when he was asked whether he was going to Respite at St Giles, he declared he wasn't going to St Giles and that he wasn't going to the Pub tonight! - and then laughed out loud! We have no idea where that idea came from. We might have to ask some questions at St Giles though!

We are watching him as he matures and hope that he is able to learn to appreciate the funny side of life.

He may never appreciate Monty Python the way his brother does – falling on the floor, cackling helplessly- but we are starting to see a glimmer!

But just today, there was another leap forward. Chris has watched a particular slapstick routine involving Rod Hull and Emu on a DVD, countless times. I found him acting out the sketch, hitting himself playfully over the head a la Emu then wrestling himself to the ground. Finally as the interviewer and his chair were tipped over into a tangled heap with Emu, Chris waited for the just the right moment on the DVD, dashed himself and a chair to the ground and thrashed around some more—all the while laughing and giggling at the silliness of it all

It was a truly magic moment!

*Many people on the autism spectrum never really come to grips with humour as the rest of us know it. This comes from a difficulty in being able to take a 'normal' situation and putting a twist on it.*

*The ASD person can be very literal and concrete in their thinking and be unable to grasp the silliness or nonsense that is expressed in a joke. Jokes to many people with an ASD are a waste of time and are quite incomprehensible. I believe this is one of the more isolating aspects of living with an ASD.*

Cheryl Scott Chris' mum

## The Hidden Autism Epidemic: How ADHD Interferes with an Autism Spectrum Diagnosis - by Diane Kennedy and Rebecca Banks

It is all too common for an ADHD diagnosis to interfere with an early, accurate diagnosis of an autism spectrum disorder, specifically Asperger's Syndrome (AS). Because children with AS often exhibit hyperactivity, impulsivity, and inattentiveness usually associated with Attention Deficit/Hyperactivity Disorder (ADHD), children on the autism spectrum are often diagnosed with a behavioural disorder.

However, this diagnosis fails to account for the myriad problems and issues associated with a developmental disorder, and as a result, children commonly receive several co-morbid diagnoses. Yet, when viewed through the lens of autism, behaviour becomes one important key to the presence of underlying social, communication, and sensory impairments, and guides professionals and caregivers toward more accurate diagnosis and treatment.

With an estimated 1 in 10 school age children being diagnosed with ADHD and an estimated 40-60% of these cases being labelled with concurrent disorders such as Oppositional Defiance Disorder, Bipolar Disorder, Asperger's Syndrome, and a whole list of others, questions emerge about whether ADHD is a complete diagnosis in itself, or, in most cases, is it a symptom upon which a disorder, and an industry, have been built?

The crux of this dilemma of misdiagnosis lies in the widespread labelling of children as ADHD. When a child obtains this diagnosis, the search for better answers to meet their needs ends, most usually with a prescription for a stimulant. However, there is strong reason to believe that ADHD is an incomplete diagnosis, especially since it is diagnosed with concurrent disorders in nearly 80% of the cases. As we proved in our last book, there is overwhelming evidence to suggest that ADHD is virtually indistinguishable from Asperger's Syndrome, a form of autism, in terms of genetics, behaviours, and impairments. Yet, because of the publicity and marketing of ADHD, along with the limited training and resulting bias of the medical community, an accurate diagnosis is often elusive or seldom found.

The best interventions for ADHD patients are also obscured by bias as well as a lack of autism awareness. The supports used in the autism community better answer and are more appropriately suited to the multi-faceted needs of most of the ADHD populations. Medical, educational, and

behavioural interventions in autism account not only for symptoms like hyperactivity, impulsivity, and inattention, but they also address the unique needs of each child through specialized training, therapies, and interaction.

Unfortunately, because the label of ADHD gets in the way of patients obtaining an early diagnosis of autism, many parents are left frustrated by the limited resources available in ADHD and blind to the help and answers in autism. Or even more frustrating, are the instances where a child has an AS diagnosis along with an ADHD diagnosis. This often keeps the professional focus on teasing out what belongs to the AS and what is part of the ADHD, thereby muddying the waters of intervention—and of diagnosis.

*The U. S. Centre for Disease Control recently announced that autism is the fastest growing developmental disability in the United States, affecting 1 in 166 children. They are calling this a public health crisis that warrants immediate attention. However, when the rates of autism are combined with the estimated 1 in 10 rate of diagnosis of ADHD, the results are staggering. It is imperative that professionals consider a broader view of behaviour—a view that accounts for the presence of underlying impairments, degrees of severity, and developmental stages—a view through the lens of autism.*

*Presented at the on line AWARE Autism Conference October 2005*

## 'Talking with Us'; Asperger's Syndrome Support Network Conference report by Geraldine Robertson

Towards the end of October I had the pleasure of being invited to speak at the Asperger's Syndrome Support Network conference "Talking with us". The conference was unusual because all speakers but one were autistic. In addition, the first day was only for people on the autism spectrum. The pleasure of a wonderful venue with a bushland setting in Brisbane and the company of so many of my peers was an incredible experience.

Speakers included Stephen Shore (Autistic Advocate) and Roger Myer (counsellor and consultant) from the USA. My friend, Dr Ava Ruth Baker of Christchurch New Zealand spoke about women's issues and health matters. Lionel Evans of Queensland presented his research project, "*Asperger's Syndrome: An Enabling Model for Individuals Living in Regional Communities*". I enjoyed seeing the diverse professions represented. Many of us work in fields which would not normally be classified as autism friendly with several

people speaking of the importance of not deciding what people can or cannot achieve, but encouraging them to find ways to work with the strengths of autism rather than to focus on deficits.

My favourite part of the conference was a panel of young people who talked brilliantly about personal experiences. Ages ranged from 12 to 17. The panel was very frank about their personal experiences. I have to say that anyone who believes that autistics have no sense of humour would have been seriously challenged by their observations.

I suggest that if you ever have an opportunity to attend an event such as this, please give it some consideration. From "flap, don't clap" to an immersion in autism culture, it is a very worthwhile experience.

## Frogs for Autism by Christina Booth (available for Christmas)

**Autism Tasmania member, Christina Booth, has made the following offer in support of AT's work.**

The following is an extract from her website

*"1 in 100 people in Australia have a form of Autism. This disorder is one that people are born with and there is no quick fix or cure. Whilst many people with Autism lead full and regular lives it can be with difficulty and not without the support of family, friends and organisations such as Autism Tasmania. Frogs for Autism is a fundraiser to help support the supporters and their Autistic relatives and friends."*

50% of the sale price will be donated to the work of Autism Tasmania. Buy a frog and help support those who live with Autism

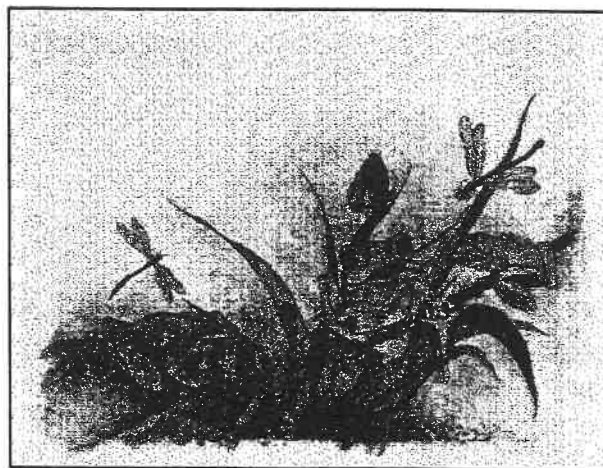
Print costs \$30.00 (Australian) not including postage and handling.

Contact Rose at Autism Tasmania or Christina Booth to make your purchase or to sell this print from your

business.

How to contact Christina:

P.O. Box 165 Kings Meadows, Tasmania, Australia, 7249. or contact Christina on 0402473795 or <http://www.christinabooth.com>



## What's happening?

### Children's Therapy Services Improvement Project:

#### An invitation to attend Community Forums

Would you like to contribute to the Children's Therapy Services Improvement Project?

Do you have issues you would like to raise with the project consultants from Evolving Ways?

This is an important opportunity to provide feedback and input in to the future directions of a range of therapy services delivered to children with an identified developmental delay, a developmental disability, or an acquired condition requiring rehabilitation.

You can have your say at Community Forums that will be held around Tasmania at the following venues

#### **Tuesday 8 November 2005**

Glenorchy Civic Centre  
Cooper St, Glenorchy

#### **Wednesday 9 November 2005**

Launceston Tram Shed  
Invermay Rd, Inveresk

#### **Thursday 10 November 2005**

Ulverstone Civic Centre  
Patrick St, Ulverstone

**Forums will be held from 9.30am – 12.30pm**

**Morning tea will be provided**

Please RSVP by Monday 31 October 2005 to:

Email: [therapy@evolvingways.com.au](mailto:therapy@evolvingways.com.au)

or

Telephone: Leanne Williams, 6214 5415

If you are unable to attend one of the forums and would like to speak to the consultants you may call 1800 803 043 (Evolving Ways may need to call you back), or email [therapy@evolvingways.com.au](mailto:therapy@evolvingways.com.au)

The Children's Therapy Services Improvement Project is an initiative of the Department of Health and Human Service and is supported by the Department of Education.

### DDA Standards now Law – A news release from the 18<sup>th</sup> August 2005

#### NEW DISABILITY STANDARDS FOR EDUCATION

More than 210,000 Australian students with disabilities will benefit from the commencement of the new Disability Standards for Education announced today.

The introduction of the Standards was welcomed today by Attorney-General Philip Ruddock and the Minister for Education, Science and Training, Brendan Nelson. The Standards explicitly state the obligations of education and training service providers under the Disability Discrimination Act 1992 and the rights of people with disabilities in relation to education and training. They demonstrate the Government's ongoing commitment to overcoming discrimination against people with a disability. The Standards have been developed through extensive consultation with education, training and disability stakeholders, as well as the involvement of the Human Rights and Equal Opportunity Commission. They clearly set out: the obligations of education and training providers in relation to the education of students with disabilities, how those obligations can be met; and what students with disabilities can reasonably expect in participating in education. The Standards apply to government and non-government providers in all education sectors, including the pre-schooling, schooling, vocational education and training, higher education, and adult and community education sectors. They also apply to providers of educational services, including curriculum and accreditation bodies. The Disability Standards for Education are available online at: [www.ag.gov.au](http://www.ag.gov.au)

## Autism Tasmania at the Hobart Show

Thanks to a great crew of 24 volunteers from Autism Tasmania and The Friends' School, Hobart Show was another success this year, albeit much smaller! Recently, National Foods decided to change their marketing direction for Pura Milk "Classic" flavours and reduce involvement at Shows – they didn't participate at Launceston; only ran one site at Hobart and discontinued their very popular showbags.

We sold a record amount of flavoured milk from one van, plus had lots of fun giving away ["sampling" in marketing language] or doing deals selling 1000 units of the new 'Cookies & Cream' Classic flavour. We think we've raised about \$1200 from the event. Carol

Webster, Keith Herd, Debb Manser & Neil Gardner all pitched in; Sharon & Jack Carter, Ro & Anita Rush had the fun job of giving away milk to the unsuspecting public! Special thanks to Nigel Geard who did a great job running the daily delivery & coordination role for the first time, split across the 4 days with Mick Clark. National Foods fundraising will be lower in 2005/06, although Agfest will continue unchanged in May next year. We're talking with them about sampling Farmers Union Iced Coffee for a fee per event at 4 – 6 speedway events at New Norfolk, Carrick & Latrobe

Mick Clark

## INTERNATIONAL ASPERGER'S YEAR

### Hans Asperger Centenary 1906—2006

FEBRUARY 18, 2006 will mark the 100th anniversary of the birth of Dr. Hans Asperger, discoverer of Asperger's Syndrome. Dr. Asperger's centenary also marks the 25th anniversary of the publication of Dr. Lorna Wing's article "Asperger's syndrome: a clinical account" in the journal *Psychological Medicine*.

Dr. Wing's paper, the first major English-language presentation of Dr. Asperger's work, helped bring worldwide attention to Asperger's Syndrome.

We invite you to observe International Asperger's Year, to be held in 2006, the year of these two landmark anniversaries. International Asperger's Year is an appropriate time to honour Dr. Asperger and other researchers, encourage people who might have AS to seek diagnosis, correct misconceptions about AS, improve and expand AS public services, develop AS mentoring programs, and recognize the special needs of AS adults. International Asperger's Year is the first worldwide celebration dedicated solely to Asperger's Syndrome. Organizations and individuals may observe IAY as they wish. The initiative was conceived by the Asperger Adults of Greater Washington, has been sanctioned by the World Autism Or-

ganization, and has Professor Simon Baron-Cohen, Professor of Developmental Psychopathology and Director of the Autism Research Centre at Cambridge University; - Professor Uta Frith, Deputy Director, Institute of Cognitive Neuroscience, University College London; - Hon. Angela Browning, M.P., Asperger political advocate and mother of an Asperger adult; - Stephen Shore, author and consultant; - Roger N. Meyer, author and advocate; - Jerry Newport, author, and inspiration for the film *Mozart and The Whale*; and - Michael John Carley, nonprofit executive.

A Committee for International Asperger's Year has established an open listserv for the exchange of IAY-related ideas, information and announcements: <http://health.groups.yahoo.com/group/asperger-year/>

COMMITTEE FOR INTERNATIONAL ASPERGER'S YEAR - AUSTRALIA Asperger Services Australia

# AUTISM TASMANIA INCORPORATED

## Statement of Income and Expenditure for year ended 30th June, 2005

	<u>2005</u>	<u>2004</u>
<b><u>INCOME</u></b>		
Autism Week	-	3,777
Button Sales	1,515	-
Commonwealth Respite for Carers	11,853	10,133
Donations	1,998	3,562
Fundraising	33,599	-
Grant	33,912	2,000
Interest	1,698	2,187
Membership	1,936	2,505
Professional Training	345	-
Seminar/Conference Fees	<u>17,413</u>	<u>1,040</u>
	104,269	25,204
<b><u>EXPENDITURE</u></b>		
Annual Return	51	44
Autism Week	360	1,060
Bank Fees	258	180
Commonwealth Respite for Carers	4,386	2,784
Executive Officer	1,200	1,840
Fundraising	26,405	-
Insurance - Public Liability	3,170	409
Library Books	263	1,793
Meeting Expenses	434	386
NAAW	-	4,837
Conference	16,759	14,569
Seminar Expenses	115	217
Sundries		
Admin Fees	-	110
Advertising	888	404
Auditing	350	300
Autism Council	194	213
IP Australia	273	-
IT Cost	1,919	1,340
Newsletter	150	-
Office Furniture	-	906
Subscriptions	-	625
Support Worker	20,464	16,405
Telephone, Postage & Stationery	3,328	1,218
Travel & Accommodation	<u>12,215</u>	<u>-</u>
	<u>93,182</u>	<u>49,640</u>
<b><u>(DEFICIT)/SURPLUS FOR YEAR</u></b>	<b><u>\$11,087</u></b>	<b><u>\$(24,436)</u></b>



## THE BULLETIN OF AUTISM TASMANIA INC.

Postal Address: PO Box 1552

Launceston, Tasmania 7250

[www.autismtas.org.au](http://www.autismtas.org.au)

*Providing lifelong support to people  
with Autism and related disorders.*

### Family Support

Contact the  
Autism Tasmania  
Family Support  
Coordinator,

Rose Clark

on

6423 2288 or

0407 320 048

or

[autism@autismtas.org.au](mailto:autism@autismtas.org.au)

This newsletter is produced  
with the kind support  
of the office of  
Michael Ferguson MHR Bass

## Parent Support Groups

### South

**South** – meet on the second Thursday evening in each month at Tascare, 231 Main Road, Moonah starting at 7.30pm. There is a Coffee Morning the following day; the second Friday (sometimes this is the 3<sup>rd</sup> depending on how the days fall at the beginning of the month) at Munchkins, in Sandy Bay, meeting from 9.30 onwards. Munchkins is located above Woolworths supermarket and is very suitable for young children.

**Cygnets** – new group about to start.

### North

**North** – no specified day or venue but get togethers are as requested by parents. Meetings have been a combination of social occasions and guest speakers.

**Exeter** – meet on the last Friday in each month at Tresca in Exeter, beginning at 10am.

**George Town** – meet on the last Wednesday evening of each month beginning at 7.30pm at the Wattle Group building located at the roundabout in Agnes Street, George Town.

### NW, West and East Coasts

**North West** – meet on the first Tuesday evening in each month at the Community Health Centre, Jones Street, Burnie (other venues according to speakers etc.)

**Smithton** – meet on the second Wednesday of every month at the Rural Health Centre in Smithton.

**Sheffield** – new group just started. No specific time or date decided as yet.

**East Coast** – meet at Scamander on days requested by parents. For meeting times and details phone Karen Rawnsley on 6372 5077

### ADULT ASPERGER'S GROUP now operational

A new group has been established in Hobart for adults with Asperger's Syndrome, or who suspect they may have Asperger Syndrome or High Functioning Autism. This group meets on a Saturday morning at Tascare at Moonah. Enquiries may be made through Rose on 0407 320 048 or 6423 2288. I am also in the process of establishing similar groups on the North West coast and in the North. Anyone interested can contact me on the above numbers.

*These groups have been established because of the desire of parents who attend them. At various times speakers are invited at others parents swap ideas/strategies/ information about services etc.*

**PLEASE NOTE:** Many of the groups have presentations from guest speakers. Dates may vary due to the guest's availability. Planning for Christmas functions and children's outings is currently underway. For information and details give Rose a ring on 6423 2288 or 0407 320 048.