



# AUTISM NEWS

## From the President

This year Autism Tasmania celebrates its tenth year and it is developing into an extremely challenging and exiting year.

During the last months the committee has been working on developing a long term strategic plan. During the process of development we are becoming more focused on our long and short term goals and are confident that this will enable us to be a more effective in representing our members.

As part of the development of a long term plan it is important to reflect on what has been achieved over the last ten years, to look at the positive developments and also the areas that are still of concern.

To this end, Autism Tasmania is hosting a public forum to be held in Launceston on the 29<sup>th</sup> of June at the Tramsheds. More information will be posted directly to you. The forum will consist speakers from a variety of services who will discuss the services they provide, 3 to 4 speakers will be grouped together and following their talks there will be the time for round table discussion and written feedback and also question and answer time, this format will be repeated throughout the day. We hope that you will come along and participate, there will be the opportunity to have a voice. CRC funding is available for members and application forms for child care funding will be available to fill out on the day.

The last committee meeting was held on the 1<sup>st</sup> of June and it was

an extremely eventful meeting and one which will have far reaching effects on Autism Tasmania. It was decided unanimously to employ an executive officer and support worker for a finite period of time. The positions will be directed under a management committee and will support us in the move from a purely volunteer organisation to an organisation with a professional face.

The executive officer will be involved in administration and the development of the strategic plan giving clear focus and direction as well as seeking financial support and fundraising. The support worker will be available to act as an advocate and support for members. We have appointed the company Brand New Day on a temporary basis, Mick and Rose Clark are Directors of the company and will be bringing to their individual roles a wealth of experience and knowledge. Once the ground work is done and the roles clarified, the positions will be advertised in the open market place and applications accepted. The successful applicant/s will be selected by an independent panel. We are hoping that this will eventuate by the end of the year.

Autism Tasmania was successful in the obtaining of a small grant \$2000 from the state government to examine and develop a brochure outlining post school options. A working party will be set up with the aim of collaborating with representatives from other autism spe-

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## DEADLINE AUGUST 17TH

The deadline for the September issue of Autism Tasmania will be 17th August. Please forward your copy to

**Cheryl Scott** on [cscott1@vtown.com.au](mailto:cscott1@vtown.com.au) or phone 63448015 a.h. to make alternative arrangements

## From the President Cont.

(Continued from page 1)

cific interest groups in order to examine service availability. If you are interested in joining the working party can you please contact me directly or write to PO Box 1552 Launceston, Statewide representation is important.

The world Autism Conference is to be held in Melbourne in November. I have had inquiries

about the possibility of funding of members of Autism Tasmania to attend. Information in regard to applications is available in this addition of Autism News. We will keep all members posted if more funding becomes available from Autism Victoria who are hosting the congress, this is dependent on Autism Victoria's application for funding from the Commonwealth Government. It is out of

our hands.

I do hope to see you at the forum in June, it is your best opportunity to openly discuss and comment on service provision in the state

Keep well and safe

Regards

**Rachel Hodge** President

## Autism Working Party

The last meeting of the Working Party took place in Launceston on 23<sup>rd</sup> May 2002.

The information in this report is taken from the minutes of that meeting as unfortunately I couldn't be present.

Kathy Wilson (Autism Consultant) gave an update of the First Links Program that now has five students operating from an Early Special Education site in Hobart.

Four students have now begun the program at the Early Special Education Centre in Launceston and there are now a couple of children on the north-west coast who can participate when the program is operational. Those present at the meeting were shown a series of videos of the program in operation with Kathy describing intentions interventions and progress. First Links,

contains an eclectic mix or program elements with parents being offered information through medical and education staff. A structure for evaluation was discussed as was Professional Development for those involved with delivering the program. The next meeting will take place on July 10<sup>th</sup> 2002 in Launceston.

**Rose Clark**

## Autism World Congress 2002 Melbourne

Autism Tasmania is preparing to buy 3 registrations to the international Autism Conference to be held at the Melbourne Convention Centre from November 10<sup>th</sup> - 14<sup>th</sup> to assist 3 personal members to attend.

If you would like to be considered for a registration, please write to the Committee for an application form.

Expressions of interest need to be received by the 10<sup>th</sup> July in order to take advantage of the early bird Concession registration \$550.00

If there are more than 3 applicants an independent panel will select the successful candidates

**Cheryl Scott** - (Secretary)

PS The website is [www.autismcongress.com](http://www.autismcongress.com). Check out the program

### 2002 Committee

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# National Autism Awareness Week

Events for National Autism Awareness Week were held on a regional basis. Throughout the state there was access to two television programs – one on SBS titled “About Us: Rats – Autism: A stranger in the family” which created much comment and the second another screening of “One Track Minds” on The Lifestyle Channel, this program featured Wendy Lawson and was excellent.

On the north-west coast there were two occasions where the media (The Advocate Newspaper) featured articles on Autism Spectrum Disorder. The first was an information afternoon at the Penguin Primary School organised by the Senior Teacher and a mother who has a child in the infant section of the school. Those people who attended, including one of the schools bus drivers were willing listeners and asked very pertinent questions. The second was a morning tea organised by three mothers, all of whom have children with Autism at the same school in Ulverstone! Despite the inclement weather a large number of people attended including a fair smattering of politicians. The morning tea raised over \$100 for Autism Tasmania and helped raise awareness of the disorder, as all three mothers spoke about their own child.

A big thank-you goes to those people who collected on our charitable collection day – one parents from the north-west ably helped by a friend raised well over \$200. That means that more than the 200+ people who wore a sticker that day found out a little more about Autism Spectrum Disorder.

We finished the week with a visit to a farm to pat and feed animals! Despite the dreary day those of us who did drive to Gawler enjoyed our visit to the Dornauf's family “Farmlet”. This was quite an impromptu invitation as they have quite a selection of animals of their own.

**Rose Clark**

**ABIT - Sharing National Autism Awareness Week!**

Most of the action for National Autism Awareness Week, NAAW, this year happened in preparation before the nominated week.

## 1. **Statewide Advertisement for Raising Awareness on Southern Cross.**

On 6<sup>th</sup> May ABIT had a Sausage Sizzle at Caldew Park in West Hobart that was a great success. Southern Cross filmed quietly and efficiently. The sausages were cooked without incident and a lovely afternoon was had by all. It was a good opportunity for those members to join us whose night time family commitments prevent them from attending the monthly Support Nights. The advertisement ran during NAAW and feedback from all viewers was positive. ABIT thanks and sincerely appreciates the commitment from those families who participated in the filming of the advertisement, also Meredith McQueen, Vice President, for her skills in the organization of filming and voice-over. At the end of the advertisement viewers are directed to the white pages in their phone books for contact on further information about autism.

## 2. **Soup 'n' Sandwich Awareness and Fundraising Function.**

Congratulations to Karen Rawnley and family, who coordinated a huge effort for Scamander to run a Soup 'n' Sandwich awareness and fundraising function during National Autism Awareness Week. Karen has been able to establish the beginnings of a support network as a result of this day. Nicole Kingston of ABAKidz Tasmania was present to talk about autism to those gathered on the day, and if the number of questions is any indication of interest, we can be assured that people in the north-east of the state are inspired. The community around Scamander must be acknowledged for their contribution of time, effort and donations.

## 3. **Message to State Primary Schools.**

2002 is the second year that ABIT has sent a message promoting NAAW to all the State primary schools in Tasmania. This year we chose a message for “Kids Only” which proved to be very successful in getting a clear and non-threatening message across to children and parents alike. Again, feedback was positive and particularly responsive to the manner of presentation. We are now challenged to maintain the standard for next year! Our committed President, Lisa Minchin, has been inundated with calls from people requesting more information about autism and also to find out about available support.

## 4. **Autism Awareness Button Stickers.**

Another simple yet effective method used to raise awareness was to send two stickers to each ABIT member. Those who wore them during the week were asked “Where did you get that?” which made a perfect opportunity for the owner to then talk about how they were involved with autism.

.....and so this year there were different ways and levels of involvement for ABIT members to participate in National Autism Awareness Week. ABIT encourages members to remember when talking to people that they are autism's best advocate!

**Rosemary Rush**

### **Disclaimer**

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

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

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

## Report: Giant Steps

*Giant Steps Tasmania celebrates its seventh birthday in July. Conceived in great anticipation and hope, its infancy has often been difficult, with the constant need to seek funding being a perpetual imperative. In the past seven years there have been significant changes to the program offered with a growing understanding that we cannot stand still: that we need to constantly keep in touch with, and learn from, research and the work of gifted educators both in Australia and overseas.*

We have, however, held on to the core of the philosophy expounded by the original Giant Steps school in Montreal: that success in autism education will best be achieved by having a range of therapies under the one roof. A multi-disciplinary and eclectic approach remains the basis of what we offer. Although we have

had to reduce our expenditure over the years, we still maintain an Occupational Therapist, Speech Pathologist, Music Therapist, Life Skills Therapist, a Specialist in Play and Social Communication, as well as Teachers.

Being mindful of the great demands placed on parents of autistic children, we have committed ourselves to reducing the financial burden by subsidising the cost of being at Giant Steps by a program of fundraising. Parents, in effect, pay less than 15% of the true cost, about 30% comes from fundraising, and the rest from government grants. We are humbled by the support which the Tasmanian community continues to provide to our children, and all the others we try to help incidentally through professional support of other educators in the field.

Some of our staff have been with

Giant Steps since it began and they often comment on the great changes that have occurred. There is a great deal more focus now on independence and students are more likely to be working without a 'shadow' directing their hand. Visits to the Self Help workshops and Line Dancing lessons are regular features of our Adolescent Program and some students prepare their lunch every day now. Our two buses are in constant use, bringing students to and from school and transporting them to a host of interesting and useful activities. Chris and Thomas will even be flying off to Darwin in July to attend the Variety Club's Annual Camp at Goanna Park. Who would have thought, in 1995, that this would have been a possibility?

**John Christie**

**Principal**

## Post School options

One of the identified priority areas for Autism Tasmania to look at is what will happen to our children when they can no longer attend school. Many of our members' children have already entered adolescence and there is real concern as to what will be available for them in just a few short years.

Preliminary investigations show that there is very little in place, for appropriate work, leisure or supported housing. It's urgent that we take up the challenge of addressing this major issue and so we call for your support. We intend to set up a working party to liaise with others interested in this concern. Can you help? Can

you afford a few hours each month to meet, formulate policies and drive initiatives?

Please ring Rachel on 6344 3261 or contact any member of the committee. This issue will not resolve itself; we need to grasp the opportunity before it's too late.

**John Christie**

## PECS Workshop

A two day PECS (Picture Exchange Communication) workshop will be held in Tasmania on October 16th and 17th 2002. You may remember that the last one

was cancelled due to lack of registrations. However as this one is being held during the week it is hoped that the times will be more suitable. The organiser of the

PECS workshop has provided us with an information and registration sheet which you will find in this newsletter. **Rose Clark.**

## Report: ABI

ABI has had some great get-togethers so far this year.

April was extremely busy with a free Parents Review night with clinical psychologist Jura Tender as well as a very well attended evening with Disability Discrimination Advocate Judith Blades. Some very worrying stories were shared by members concerning their experiences of inclusion.

We have yet to decide how best to respond to members needs in this important area and will consult democratically -as always - with our members before taking a decision. Solicitor Judith Blades has extensive experience and impressive knowledge in the area of advocacy for people with disabilities and she told us that families of children with autism have made the most enquiries to her out of all the disability groups in Tasmania so far. The response to the Southern Cross Television Autism Aware-

ness Week Ad - which ABI organised and paid for, has been overwhelmingly positive and we are very grateful to our talented Vice President Meredith McQueen whose concept it was and who did such a great voice-over for the ad. Since that publicity as well as a piece especially for kids" sent out by our dedicated Secretary Rosemary Rush which was published in many state school newsletters we have been inundated with enquiries from families and others offering to help.

Our May support night was well attended and we hope to see old and new members along at:

**June 12** - siblings outing to Cadbury's RSVP to Ro Rush 62 29 5760 or  
<rushm@netspace.net.au>

**June 19** support night at Ro and Martin's 48 Drysdale Ave Kingston 62 295760 from 7 pm

**July 17** support night at Joy and Alan Hoyle's 279 Roslyn Ave Blackmans Bay 7pm

**August 21** our 5th AGM at Lisa and David Minchin's 4 Lasswade Ave Sandy Bay from 7.30 pm ph 62 232317.

We continue to support members on various Education Department groups such as the PRG, IEP working group and the Autism EI Pilot. Our library of resources is growing and we have been extremely grateful to the Hobart Ionians who have supported us throughout this financial year.

ABI has been re-energised by new members and by our never-ending commitment to support families teaching ABA. Best wishes to all,

Lisa Minchin President ABI

## Letters to the Editor

Dear Editor,

My name is Tameka Dornauf and I am married to John. Together we have 4 children, Alexander 6 (autistic), Whitney 5, Benjamin 14 months and Hannah 3 months.

I was thinking about the newsletter and wondering if we could include a parent to parent page where parents could send in photos and brief stories, achievements, coping strategies, questions, advice and that sort of thing.

I know at times I am very proud of my young man but have no-one who truly understands.

How proud I am that he can skip 2 times on a skipping rope, which he has just learned to do; but to my friends of NT kids, that is something their kids can do easily - no big deal they say, but it is a big deal for my autistic child.

It would be nice to share experiences with people who truly understand and,

who knows, maybe some great friendships can be made. I know at times I feel very alone in all of this.

Also maybe we could have some seminars etc arranged for the NorthWest coast of Tasmania (I am from Ulverstone area). I would love to attend some of these meetings in Hobart and Launceston but it would be impossible for me to do so.

And on another note - I loved the siblings article. Keep up the good work!

Thanks Tameka

*Dear Tameka,*

*Thanks for your suggestions.*

*I hope that members will follow your example and share some of their experiences through our newsletter. Ed*

*Tameka's story is on page 11*

Dear Editor,

Thank you for your newsletter which I

always read with interest. I wanted to comment on the "potted comparative summaries" of various treatments for ASD published in the last newsletter.

I personally find the gross oversimplification that such exercises require not to be terribly useful to anyone as oversimplification can cause misinformation, albeit unintentionally. The summary of ABA was rather out of date and perpetuated the negative image of this therapy which dates from methods from the 1970's which have been superseded by much more effective and up-to-date techniques in the past decade.

I will endeavour to provide readers with a more accurate picture of current ABA methodology in a future edition of Autism News.

Yours sincerely, Lisa Minchin

## Seeing is Believing Bereavement Support in Practice: excerpts from an article by Valerie J Baxter

When a death occurs in the close social network of a person with an intellectual disability, they may be disadvantaged as regards to understanding what has happened and being enabled to commence grieving.

Firstly, education about the nature and permanence of death may have been overlooked for a variety of reasons. Death education commences for most of us in childhood, gathered around a dead bird in the back yard or at the child care centre. It often includes a tricky question and answer session in a trusting environment followed by grave digging and flower petal ritual. The death education process thus continues through partings from much loved pets to grandparents with picture books to help us understand the reality and accept the feelings associated with such a loss.

Many adults with intellectual disabilities have been cut off from early death education experiences, particularly if they grew up in institutions. Presumptions have often been made that "they just wouldn't understand". For others, caring adults may have been intent on protecting them from anything sad. Sometimes, the resources and confidence to broach the subject have been lacking.

A second reason for people with intellectual disabilities being disadvantaged in terms of opportunity to understand death is that death is a confronting subject. It's mention confronts us with the prospect of our own mortality and that of our loved ones. As a result, it is sometimes not raised with our clients until 'the inevitable happens' because for all of us avoidance is a natural response

to subjects we find uncomfortable

Thirdly, death is a difficult concept to understand, quite difficult enough without including the possibility of an after-life! It is made even harder to understand, because the subject is still surrounded by euphemisms, metaphors and taboos. If an individual has significant cognitive limitations, this understandably makes the concept even more difficult to grasp.

.....people with intellectual disabilities may be disadvantaged in understanding that death has occurred, by not being included in appropriate ritual events. In

**"Many adults with intellectual disabilities have been cut off from early death education experiences, particularly if they grew up in institutions"**

my own childhood in the fifties, funerals were still male-dominated events,

.....I would now like to pose and attempt to address the question of how such inclusion can be best promoted. A death in the family often touches three or four generations. Inevitably, when there is doubt about who is to be included or excluded, the wishes of older family members are generally respected. Older family members may believe that the person with the disability should be protected from attending a funeral, or that they may upset others by vocal and behavioural expressions of feeling. Family members may also feel vulnerable about what others present may think or say.

It is appropriate to gently encourage relatives and carers to

include the person with the disability in the rituals, without beating the drum of client's rights to inclusion too loudly. It is important that staff offer to support the client at this time, as relatives may not feel that they have the capacity to do so when they are grieving themselves. Remember that the appropriate staff to be involved are those who are not grieving over a loss in their own lives at that time. Explain to relatives that participation in the rituals will help the person with the disability.

It is also true that when the first parent dies, adult siblings of the person with the disability may be especially protective of the surviving parent, and of their perceived needs. This may be a reason given for reluctance to include the person with the disability in appropriate rituals. In such an instance, it is the responsibility of staff to request assistance if need be, and to gently nudge the family along toward the realisation that it will be in the best interests of the client to be included. The most persuasive argument is generally that it will help the person with the disability to understand the finality of death and will enable them to commence working through their grief. It may also assist in avoiding behaviours caused by the frustration of not knowing what has happened.

.....a request to accompany the client to a private individual body-viewing farewell is seldom refused. Originally I stumbled on this idea as a compromise for not attending the funeral, but I have now come to believe that it is more meaningful for many clients than funeral attendance, particularly for people with a

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## Seeing is Believing Bereavement Support in Practice ...continued

*(Continued from page 6)*

high level of disability. When a significant death occurs, our principal task as workers is to assist our client with an intellectual disability to understand what has happened and to connect with their feelings associated with the loss. As I read from the account of a residential service manager who supported a client in this way, you will understand why my paper is titled 'Seeing is Believing'.

*How do you tell someone with substantial hearing loss, no verbal communication skills, unknown cognitive recognition skills and an intellectual disability that their mother has just died? How do you prepare them for the pain, the anger and the enormous sense of loss that accompanies this dreadful news? How do you prepare them to say goodbye through a viewing of their mother's now lifeless body and them support them to participate in the societal rites of passage in order to begin the process of grief?*

*The situation poses many challenges, and sets you upon a journey of inward reflection about the work that we do and the people whom we support. David's mother died suddenly. The phone call that broke the news to me sent me into a bit of a spin. This particular challenge was new to me. My immediate reaction was that David should know and that he would need a hell of a lot of support. Fortunately David's family presumed that he would be involved in all aspects of the rites of passage. They also quite rightly presumed that they would be needing all of their emotional energy and would be unable to assist him at this time and that we,*

*as his residential service provider, would do whatever was needed to ensure David's full involvement.*

*David's siblings went to his home and broke the news to him. What he understood will never be known, but if the words and pictures had no meaning the emotions spent within the room whilst he was told most certainly gave him the clear understanding that all was not right with his world.*

It is important to remember that for everyone, the majority of communication messages are received through the non-verbal channel. We all receive and react to tone of voice, body posture and facial expression, more than to what is actually said. A client's understanding that death has occurred may come only gradually and through diverse means of communication. That understanding may sometimes be partial and difficult to assess.

.....The family agreed that he be given the opportunity to say goodbye to his Mum. The agency manager decided that she would be the one to support him through the experience because she had an existing relationship with him and because his behaviour could be quite challenging, and sometimes aggressive. She was not comfortable placing a staff member in that situation. In her words:

*"The issue of seeing and touching a dead body is a taboo subject for many of us. People's own values, attitudes, fears and past experiences come into play so much that this is not a request I would place on to any other person, unless they volunteered and could demonstrate that they had the emotional reservoir to cope with the situation."*

I believe that the private farewell to the body of the deceased loved one is very important, and can be particularly meaningful to some people with severe disabilities. Seeing the difference between a living, moving, changing, expressive face and a totally still one with a fixed, though tranquil expression, is to know that a profound change has taken place. Feeling the difference between soft, warm, living flesh and firm, cool dead flesh, can be the pathway to understanding that: "Death is final and permanent and that once a person is dead they stop all bodily functions such as sleeping, breathing and talking."

Another advantage is that the body-viewing farewell is a private and personal occasion, during which loud or disinhibited behaviour will offend no-one. The client can be relatively in charge and there are often less time constraints than at funerals. The occasion may also serve as excellent preparation for attendance at the funeral and wake. Now to return to the words of the residential service manager, describing David's private time at the funeral parlour:..... *In David's case we didn't know if he had understood what we had been signing and saying to him about death...I entered into David's journey with nothing more than a deep sense of care for him as a fellow human being and a deep sense of respect for the fact that disabled or not he had every right to do what any son does in the event of the death of his mother - to grieve. I visited David a couple of times before the viewing and we looked at pictures and compics of relevant themes. At times he shed tears and at others he looked at me blankly...On the*

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## Seeing is Believing Bereavement Support in Practice continued

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morning of the viewing, David's house staff supported him to dress well and talked with him through basic sign about where he was going and what was going to happen. He responded by hitting them. When I arrived at the house we had coffee together and went through a display book that I had prepared which told the story of what had happened to Mum and about how he was going to say goodbye to her. David appeared to be interested in the story and looked at all the pictures carefully, but had no response apart from wanting to get out of the house. I wondered where he thought I was taking him...out for lunch maybe...this concerned me. As we arrived at the funeral parlour I could see and sense that David was becoming a bit anxious, as was I. On entering the chapel we were shown through to where his Mum lay...A multitude of thoughts bombarded me: What was I doing? How dare I put David into this situation...when I did not know if he had the emotional capacity to understand and to process the experience. Was I about to abuse him (with the best of intentions) for the sake of political correctness and the inclusion factor? What right did I have? Who did I think I was? By this stage we were being ushered in to the quiet room with the beautiful, but so identifying scent of funeral parlour pervading the air. The journey was about to begin and like it or not I was a passenger... The attendant came with us into the room. David rushed to his Mum's coffin and within a split second of looking at her he 'broke down' and screamed. His grief was primeval and I mean that in no derogatory sense at all...He screamed, cried painfully,

grabbed at his clothes, hit out at me and pulled at his hair, exhibiting classic signs of shock and grief. This continued for some time, but when he regained his breath, he stood and took time to look carefully at his Mum. I encouraged him to touch her hands, to feel the difference warm and cold, dead and alive. He then became very angry, hit me, screamed at his Mum and then left the room. I followed him and realised that he was signing for

**"We stayed for over 45 minutes and during this time I witnessed something that I shall never forget, something that was such an honour and privilege to be part of."**

the toilet, which we located. He regained composure there, so we left and sat in the larger chapel that adjoins the viewing area.

We talked through sign and verbal communication and I ensured that he had two clear choices - to go home or to go back and see Mum. David chose to go back and see Mum. We stayed for over 45 minutes and during this time I witnessed something that I shall never forget, something that was such an honour and privilege to be part of. I witnessed the shifting of emotions, the working through of a process of which I would never have given David the emotional capacity to work through before. He spent 'time' with his Mum. He touched her gently, he verbalised to her, he signed to her, he cried, big silent tears. In all he spent about 40 minutes talking 'with' and about his Mum, with tears but without aggression. There was a sense of acceptance with absolute sad-

ness, but acceptance. He insisted that I sign back the sign for 'dead' to him whilst pointing at his Mum over and over again. The finality of the sign must have meant absolute realisation for him.. The time that we spent was amazing, it demonstrated to me that regardless of a person's disability there is, within us all, an intrinsic sense that lets us know as human beings that another person is dead, that they're not asleep, they are actually dead. David went from absolute pain and agony during the first few minutes of exposure to his Mum to acceptance that she was dead. Perhaps he finally realised the meaning of all the pictures that had been pushed under his nose during the days before. Eventually, and at David's choice and timing, we left the funeral parlour, not without a final farewell and wave at Mum's coffin. As we returned to the house David appeared at ease, though a touch sad. I left him with lots of communication about Mum's funeral in two day's time. The day of the funeral arrived...David was ready and waiting. We did the communication thing with the book, this time with 'funeral' photos and different compics...I was still unsure as to how much David understood about what was happening and if he made any connection between what had happened two days before and the funeral ceremony.

We arrived at the funeral parlour. I had already arranged (in my head) the best place for us to sit. How dare I be so presumptuous! The funeral parlour attendants remembered us from the viewing, welcomed David and as a member of the family ushered us up to the front row. We found ourselves

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## Seeing is Believing Bereavement Support in Practice continued

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sitting up front and centre, smack bang in the middle of the entirely packed funeral chapel. David was pleased by this and looked around excitedly, verbalising loudly and pointing to his Mum's coffin...David was besotted by the pamphlet given out, which had his Mum's picture on the front. He spent the entire service gazing at the photo of his Mum, looking over at the rest of his family and verbalising.

At the conclusion of the service David joined the rest of his family for the wake. He had lots of sandwiches and coffee and enjoyed meeting up with people who hadn't seen him for years, not since he was a small boy...The sense of family was strong and I was honoured to be re-introducing David to people who were long-

term family friends who had often wondered what had happened to him after Willow Court. Most were amazed to find out that he was living in a house in the suburbs and doing just fine.

*I feel that the funeral service meant, not a lot to David. He went because he was taken, he sat and he listened. This particular ritual was lost on him. He had done his serious grieving a few days beforehand. However I feel that if he had not had the opportunity to see and be with his Mum beforehand and had just been taken to the funeral, then his reaction may have been a lot more volatile.*

*When we finally left the wake, I gained a sense from him that was like 'so that's that...that's what you meant...he wasn't any more sad than before, but I feel he understood. We went home and David took his Mum's eulogy pamphlet into his room. I received the message that I was no longer needed and could leave.*

*Upon reflection...an amazing experience. I now totally believe in absolute inclusion in the entire death/grieving process. All the rituals that we have in our society are important, and our clients need to be involved in all of our rituals. Never, ever say or even think to yourself, "they won't know" "it won't mean anything to them". They will know and it is important to them and it is a basic human right. To be exposed to the death of a parent, sibling or friend is painful, it hurts, but it is a basic human right to be exposed to that hurt and not hidden from it. Hiding someone from the hurt is, in the long run, much more painful than the exposure. Never*

*ever discredit someone with the capacity to feel, regardless of the disability. Never ever deny them the opportunity that is afforded to you and I to say good-bye.*

Finally, I am interested in sharing and hearing about available resources. I'm also interested in ideas of how to help clients to retain memories of loved ones they have lost. The pamphlet from David's mother's funeral service became a treasured memento, as it included her photograph. Using a little time and creativity, I have found that it is possible to assist clients to construct memory books or boxes containing visual and tactile reminders of the loved person who has died. If the deceased was a friend or co-resident, then pages could include brochures and photos of places friends have visited together, photocopies of favourite music tapes, labels from preferred foods - anything which evokes memories of the person who has died.. Relatives may wish to reclaim photographs, but seldom object to them being scanned to first make copies. A snippet from familiar slippers or a shirt or skirt, has tactile as well as visual attraction, and even a lock of hair may not be inappropriate - best if the client can choose. Adhesive photo albums or display folders are suitable and cheap.

We can all identify with the comfort of making or doing something to honour a deceased person we have loved or respected. We can all identify with the consolation of keeping a treasured memento of that person. Memory books are one way in which we can support clients to maintain memories of the deceased in a form which becomes a keepsake

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### AUTISM SUPPORT GROUPS IN YOUR REGION

**Autism Southern Support Group**  
Contact Janet Smith on ph. 62591149

**Autism Northern Support Group**  
Contact Sue Thorogood on ph 63681131

**Autism North Western Support Group**  
Contact Rose Clark on ph 64231086



# Special Education Services in Tasmania

*This is an extract from the publication "Students with Disabilities and Difficulties with Learning", produced by the Department of Education, Equity Standards Branch, March 2002. ACD has had a number of recent queries requiring clarification about the Category A register moderation process, funding for students on the Category A Register, the difference between the State Support Service and District Support services etc. and this article is a very good starting point for parents wishing obtain more information on these subjects.*

## SPECIAL EDUCATION SERVICES

Tasmania is divided into 6 education districts: Arthur and Barrington in the North-West, Esk in the North/North-East, and Derwent, Bowen and Hartz in the South. Each education district has a district support service.

### *What are District Support Services?*

Each district support service is responsible for the equitable provision and coordination of a range of specialist services to schools. Specialist services include speech and language pathology, guidance (educational psychology), social work, specialist teachers and aboriginal education workers.

The support service works collaboratively with schools. The aim is to provide a range of support that enhances each school's capacity to provide a quality education for all students, and to maximize educational outcomes for students who present with challenging behaviour, and for students with learning, intellectual and communication disabilities, and/or emotional or social difficulties.

There are several levels of delivery

of this service. They include professional learning, resourcing, and case management for individual students. The support service actively promotes and plans a range of programs, interventions and strategies which encourages students to be part of the learning process and to work independently.

District support services work closely with the State Support Service with the aim of providing a continuum of support for those with the highest support needs. The support services also develop networks with other community groups and government agencies involved with young people and families.

The support services work within the framework of a number of key Department of Education policies and guidelines and relevant State and Commonwealth legislation. Of particular relevance are the Equity in Schooling Policy, Inclusion of Students with Disabilities Policy, Enrolment and Attendance Guidelines, Discipline Guidelines and the *State Anti-Discrimination and Disability Discrimination Act 1992* and the *Commonwealth Anti-Discrimination and Disability Discrimination Act 1998*.

### *What is the State Support Service?*

The State Support Service provides a structure to unify, coordinate and manage specialist and statewide services for students with vision impairment, hearing impairment and Early Special Education.

The State Autism Consultant and the Physical Impairment Coordinator, also under the auspices of the State Support Service, provide specialist and statewide services in those areas of expertise, working closely with district networks.

The service is responsible for ensuring that students with low incidence disabilities are adequately supported to access appropriate education. The number of students with vision or hearing impairment is relatively small and occurs randomly across the State. The total number of students with these disabilities is too small to accurately predict numbers in each district and resource accordingly through district structures. It is therefore appropriate to provide services using a statewide, across-district model of service delivery. This ensures appropriately qualified and trained staff can be flexibly deployed across the State to meet the specialist and changing needs of this group of students.

Early Special Education Services are also the responsibility of the State Support Service with 4 regional centres in the State. The number of students involved is relatively small and the family-focussed service provision for 0-4 year olds is significantly different from school-based services.

## SPECIAL EDUCATION PROCESSES AND RESOURCES

Special education resources in Tasmania are allocated by 2 different processes, central resource allocation and district resource allocation.

### *What are central special education resources and how are they allocated?*

Central resources are administered by Equity Standards Branch and are overseen by the Special Education Advisory Committee (SEAC). They include resources to support students on the Category A Register as well as other special

*(Continued on page 11)*

## Special Education Services in Tasmania cont.

*(Continued from page 10)*

education programs which support students with disabilities across the State ( eg Transport Assistance Program, Minor Works for Students with Disabilities, Information Technology for Students with Disabilities etc). The Category A Register is discussed more fully below.

Special education resources are also allocated centrally to the State Support Service to facilitate access to appropriate education opportunities statewide for students who are vision impaired or hearing impaired, and young children enrolled in Early Special Education Services.

*What are district special education resources and how are they allocated?*

Special education resources, including resources to support students who are not on the Category A Register, are also devolved to district support services, by SEAC, to allocate at the local level in response to identified needs within the district. These resources are referred to as *district resources*. The allocation of these resources is overseen by District Special Education Committees.

District (non-Category A) resources are provided for students who have less severe disabilities or problems with schooling in a more general sense. These students may have mild to moderate intellectual disabilities, Autism Spectrum Disorder, specific learning difficulties including ADHD and dyslexia, specific language problems, emotional or behavioural difficulties. These students may or may not have a specific diagnosis.

District special education resources are allocated to each district in recognition of the fact that

the needs of these students can be identified and addressed most effectively and efficiently at a more local level. Decisions about the allocation of district resources are made by District Special Education Advisory Committees. District resources are used to support individual students and to support specific purpose programs or projects designed to meet the identified needs of groups of students.

Each district's special education allocation is determined by a formula, which includes the total number of students in the district and the Educational Needs Index, which takes distance from centre and socio-economic status of the school into account. Each district also attracts funding specifically to support students with challenging behaviour in addition to special education funding.

*What is the Category A Register and how does it work?*

The Category A Register identifies those students for whom the functional and educational impact of their disability is **most** severe. These students generally require substantial, often highly specialized, support throughout their school years in order to access appropriate education and achieve appropriate educational outcomes. Students on the Category A register are supported from central, rather than district special education resources.

Eligibility to access central special education resources is determined by a statewide **Category A Moderation Process** which determines each individual student's eligibility to be placed on the Cat A Register.

Specific areas of disability identified on the Cat A register include: intellectual disability; Autism

Spectrum Disorder; Physical Disability (including Health Impairments); Psychiatric Disability; Vision Impairment; Deaf and Hearing Impairment; and Multiple Disabilities.

Relevant detailed information about each of these registers, including eligibility criteria, and the documentation required to support a student's nomination is available.

*How are students nominated for the Category A Register?*

Students thought to be eligible for the Category A Register are nominated by their school, in conjunction with the relevant support service.

Nominations are endorsed by the relevant District Support Service Manager, or the relevant State Coordinator in the case of students with vision or hearing impairment or those students who have been supported in kindergarten by Early Special Education Services, and then forwarded to the Moderation Committee.

Moderation committees, for each of the identified disability areas, are chaired by the Manager, Disability Standards and include a range of professionals from around the State, who have specific experience and expertise relevant to the area of disability being considered.

Decisions regarding each student's eligibility are made on the basis of written documentation provided to the committee. Clear guidelines are published, detailing the information that is required by the committee in order to make fair, informed decisions about each student's eligibility. Published eligibility criteria are applied to ensure the integrity of the

*(Continued on page 12)*

## Special Education Services in Tasmania cont.

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moderation process.

Moderation committees reserve the right to ask for additional information about nominated students to help them make the most appropriate decision about a student's eligibility. The source and content of any additional information will be recorded in the Minutes. To help make informed decisions, a representative of the Moderation committee may visit a student being nominated for the Register to observe his/her functional behaviour in the classroom.

Each Moderation committee provides feedback to the relevant District Support Service Manager or State Co-ordinator about each student's eligibility for the Register. This information can be provided to schools and parents/carers. If a student is considered ineligible for the Register, the nomination (with additional information) may be submitted at a future round of moderation, if the school and/or parent/carer wish.

### *What is the role of parents/carers?*

Nominations for the Category A Register should be made with parents'/carers' permission and ideally with their participation and input as appropriate. Information about the moderation process and eligibility criteria should be made available to parents/carers. The information contained in this package is important for them. Parents/carers can provide written information to the committee if they wish.

As soon as possible after Moderation committee meetings, parents/carers should be advised via the relevant Support Service Manager or State Co-ordinator whether or not their child has been placed on the Register and

the reasons for the decision. Documentation provided by the committee can be used for this purpose.

### *What does 'Review' involve?*

Students placed on the Register may be subject to review to ensure the continuing appropriateness of their placement on the Register. If a review is required the Moderation Committee will usually identify the need and time frame for review when the student is placed on the Register.

It is the responsibility of the school/district to provide relevant information about students identified for review.

### *What is the relationship between the Category A Register and Funding?*

Because of the severity of their disability, students on the Category A Register have first priority for special education resources. These students are resourced on an individual needs basis taking into account the educational impact of their disability and the context in which they are being educated.

Funding for students on the Category A Register who are enrolled in regular schools is 'tied' to the individual and subsequently moves with the student if he/she moves to a different regular school within Tasmania.

Students on the Category A Register who attend special schools are funded at the beginning of each school year using a formula that recognizes the different circumstances which apply in special schools.

Placement on the Category A Register does not guarantee any par-

ticular level of funding. It identifies those students will be resourced from central, rather than district, special education funds. It is not the purpose of the Category A Register to identify all students with disabilities. It is acknowledged that there are some students with significant disabilities or problems with schooling who are not eligible for the Category A Register. These students are supported from district special education funds. There are students who are not on the register, who at certain times in their education, may attract more resources than some students on the Category A Register. The nature of students on the Category A Register however means that the severity of their disability is lifelong and their need for significant, often specialized, support will remain throughout their schooling.

## To brighten your day

Dear Lord,

So far today, am I doing alright?

I have not gossiped, lost my temper, been greedy, nasty, selfish or self-indulgent.

I have not whined, complained, cursed, or eaten any chocolate.

I have charged nothing on my credit card.

But I will be getting out of bed in a minute, and I think I really will need your help by then!!!!

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## About Asperger's – by Geraldine Robertson

A friend asked me what I would have told my son's teachers if I had known that both he and I had Asperger Syndrome. These were my thoughts.

1. Autism is intensely logical. Every behaviour represents communication - your job is to observe, to put away your assumptions and to detect the intent of the behaviour. For example, my class was on an excursion. The children were asked to put their backpacks in a small room while we toured the building. An autistic child became very distressed. People were trying to tell him that his backpack would be fine and that he could get it when he returned. The child was getting more and more upset. The solution was found by putting the backpack back on and observing. Immediately he started to calm. I put another heavy item in the backpack. Like magic he smiled and lined up with the others. It was a sensory issue. Unfortunately, I had to tell the people conducting the tour that either he was allowed to wear the back pack or the excursion could not continue. I had to emphasise that this was an equity issue. Permission was granted.

2. When observing autistic people, the behaviour you see does not necessarily reflect the emotion being felt. Fear is often a smile or a frozen body. The child stimming by bouncing a ball in the playground day after day is not necessarily content. He/she has just found a way of being in the playground. The child smiling while making mistakes with his/her work is not likely merely to be teasing you. No assumptions can be made about autism.

3. People often complain that children with Asperger's are manipulative. The complaint is that they challenge authority and enjoy doing so. It helps to think of the child as a scientist hypothesizing and testing theories about the social world. They modify variables, gather data and yes, they can enjoy the process. Would you think it wrong if a scientist enjoyed her work? We know that people who are motivated and enjoying their work learn more effectively. Autistic people are the same.

4. Autistic people do not have a communication problem in isolation. The problem arises when two people who do not share the same communication system attempt to exchange information. This is true for language, for cultural communication eg body language and for knowledge and value systems. Everybody in the autistic person's community is a part of the problem, and everybody has to be a part of the solution. The challenge for schools is that the whole community to be informed and to be taught explicitly to value difference and to cope with the problems that may arise. Both teachers and teacher aides also need to be explicit when working with small groups of children so that they learn appropriate ways to approach an autistic person, as

well as vice versa.

5. An autistic person may perceive the world very differently. This is not imagination. It is their reality. Letters can be sounds. Feelings can be colours. When you are telling a child that c-a-t is cat, beware. I can remember clearly the day, 46 years ago that the teacher wrote "ch" on the board in green. I was excited for days because she got it right. That was the first and last time she did. If you imagine the chasm in learning that the child must overcome, patience may be a little easier. If the child is struggling, ask what colour a letter is or how it tastes. You may be able to map the alphabet in a meaningful way.

5. Emotion can be experienced in many ways. If a person cannot understand what you mean by surprise, sadness, disappointment etc, perhaps feelings are experienced as colours or sounds or perhaps they are body sensations. Unless you know, discussion goes nowhere.

If the person on spectrum has a problem with an emotional context, let him/her draw what happened. The drawing can be used to clarify discussion. The autistic person then has a point of reference and is less likely to be manipulated or set up by others in a conflict situation.

7. When educating people about autism, provide a sensory experience. Hand out sandpaper to be placed inside undies. Turn the lights on and off very fast and tape a loud regular noise to play while they are doing a comprehension exercise which has some key words whited out. Get snaky if the audience does not stay on task.

8. Remember that people on the autism spectrum exist in intense isolation. Denying them information about who they are perpetuates this. It isolates them from the support of peers and condemns them to struggling alone to explain the inexplicable. In my opinion this is abuse. Information about autism is widely available. There are adults who have learned to cope through a process of emotional pain and humiliation. Many are present on the internet and in communities, desperate to ensure that the children do not suffer. Please do not make assumptions that Autism/Aspergers is too hard to bear. Not knowing is too hard to bear. Finally, no child chooses to be disliked, criticized or punished on a daily if not hourly basis. That is not logical and nor is it autistic. Remind people that what is said cannot be unsaid. Remind them that childhood is short and that we only get one chance at it.

**Geraldine Robertson**

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## Parent Reference Group (PRG)

There have been two meetings of the PRG this year, one in March and the second one in May. We have had some important discussions and outcomes which are included in the detail below.

### At the March meeting:

- It was reaffirmed, after general discussion, that PRG members are representing established, recognized associations supporting parents/families of children with a disability. Members are not there to represent their own personal views.
- Kerry McMinn clarifies the sequence of events in relation to discussion regarding the automatic placement of students with Down Syndrome on the Category A Register. It was reaffirmed that at this time there has been no change in practice in relation to this group of students.
- After a question relating to the "cut-off point" between Cat A and non Cat A children and about how we compare to other states, Herry stated that it is not possible to do a direct comparison with other states" base level for Cat A, because other states have differing allocation processes and do not have Cat A registers.
- Kerry reported on the meeting between Tas Council and Equity Standards Branch in December 2001, which resulted in some changes to the operations of the PRG. In order to most effectively facilitate the functions of the PRG, in terms of the Department of Education providing accurate, current information to parent organisations and SEAC (Special Education Advisory Committee) seeking parental input into decision making, it was decided that Kerry should convene the group. She assured the group that she would accurately report the PRG's views to SEAC and this will be reflected in the SEAC minutes and the working group reports, which members of the PRG receive.
- It was agreed that lobbying is not the role of the PRG.
- Concern was raised about the lack of repre-

sentation of the PRG of ADDSUP.

- The redrafted Cat A register information and guidelines were discussed and PRG members suggested a few minor but important additions which Kerry will incorporate into the next draft.
- **Parents are being reminded that the criteria for eligibility to the various registers is not being changed in these drafts.**

### The May meeting:

- It was decided that Kerry will write to ADDSUP expressing concern about the lack of representation from their organisation which offers support to parents of children with ADD and ADHD.
- Di Fuglsang reported that the Board of ACD "agree that we acknowledge that there are inequities (in relation to students with Down Syndrome and the Cat A register) but we do not agree to one particular inequity being addressed without the range of inequities being addressed".
- It was decided that Kate Shipway from Equity Standards Branch be asked to attend the next PRG meeting to discuss with members their concerns about lack of parent consultation in relation to Recommendation 42 of the Inclusion Review which states that "The Department of Education works with the Tasmanian Principals Institute and the Department's Professional Learning Services Branch to develop professional learning programs that address the leadership qualities required to enable a school to build capacity for inclusive education in all its various forms. Parents and organisations that have expertise in particular disabilities should be consulted in the preparation of these programs." Implementation of this recommendation has been defined as high priority by SEAC.

Kerry clarified the way in which the Cat A shortfall is funded. Some members believed that the shortfall was addressed by taking money directly from Non Cat A funding. This is not the case. The districts were asked to make a 9% cut to their funding submissions for students on the CatA register and districts then use different strategies to accommodate those cuts. This is a very different case scenario from actually taking funds away from non Cat A children to fund Cat A children – there seems to have been confusion for parents regarding this difference.

## Parent to Parent

Hello,

My name is Tameka and I am married to John. We have 4 children, Alexander 6, Whitney 5, Benjamin 15 months and Hannah 4 months. We live at Gunns Plains, just outside of Ulverstone.

I was always waiting for Alexander to become "normal". I even verbalised this to friends and family. I thought he was a challenging child, who was eccentric and I called his behaviours "Alexander's ways". I was to learn that many children and adults shared these "ways" and there was a word that described it - Autism.

Suddenly the flood gates opened and many, many questions were answered. No longer did I have to make excuses for his odd behaviour or strange movements, and now above all we could help our son and understand him a little better, and with extra assistance he could learn to



understand us.

Alexander attends West Ulverstone Primary School and is in grade 1. He has very understanding teachers and a supportive network there.

I am as proud as I can be of my little boy. He is a golden haired blue eyed Aussie kid who enjoys computers and the Playstation and has a special love of trains. Although he has his difficulties he has many special qualities and skills. It is the delight in

his eyes as he says "I can do it" that makes the heartache and perseverance worthwhile.

I know he will develop at a slower rate and that he will have many more difficulties than his peers and his siblings. But it is with the support of other parents of children with ASD and Autism Tasmania that I can rejoice in his small but empowering achievements such as tying his shoe laces, or losing the training wheels from his bike.

I look forward to reading about other Tasmanian children on the spectrum and their families in future newsletters. Maybe we can encourage and enlighten each others days with a few words.

with love  
Tameka Dornauf

*If you would like to share your triumphs and tribulations with our members, please e-mail your contributions to the editor at [cscott1@town.com.au](mailto:cscott1@town.com.au)*

### STOP PRESS

### POST SCHOOL OPTIONS FUNDING

IF YOUR CHILD IS LEAVING SCHOOL THIS YEAR.....

PHONE YOUR LOCAL DISABILITY SERVICES OFFICE

TO REGISTER YOUR CHILD

FOR THE ABOVE FUNDING

BY EARLY JULY

## Newsletter of Autism Tasmania Inc.

Postal Address  
PO Box 1552  
Launceston  
Tasmania 7250  
Australia



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



*(Continued from page 9)*

In closing, I wish to acknowledge permission given by David's next of kin to use his story. His name has been changed for the purpose of this paper. I also wish to express my gratitude to the Manager of his residential service for the written account she provided at my request. It is her story as well as Davids'. She has given permission for the material to be used in my paper but her name and that of the service have been omitted in order to maintain confidentiality.

*This is an edited version of a paper delivered at the ASSED Conference in 2001 by Valerie J. Baxter, who is a Social Worker with the Resource Team at Disability Services (South) Although the content of the paper is aimed at support workers, Autism Tasmania feel that parents will also find the information helpful. If you would like a copy of the full paper, Val can be contacted at:*

**Resource Team,  
Disability Services (South)  
Ph: 6230 7600  
Fax: 6230 7605**

### Effects of a Weighted Vest on Attention to Task and Self-Stimulatory Behaviours in Preschoolers with Pervasive Development Disorders.

Study done by Fertel-Daly, Garry Bedell and Jim Hinojosa.

The following is the introduction to the article which appeared in The American Journal of Occupational Therapy.

**Objective:** This study examined the effectiveness of using a weighted vest for increasing attention to a fine motor task and decreasing self-stimulatory behaviour in preschool children with pervasive developmental disorders (PDD).

**Method:** Using an ABA single-subject design, the duration of attention to task and self-stimulatory behaviours and the number of distractions were measured in five preschool children with PDD over a period of six weeks.

**Results:** During the intervention phase, all participants displayed a decrease in the number of distractions and an increase in the duration of focussed attention while wearing the weighted vest. All but one participant demonstrated a decrease in the duration of self-stimulatory behaviour while wearing a weighted vest; however, the type of self-stimulatory behaviours changed and became less self-abusive for this child while she wore the vest. During the intervention withdrawal phase, three participants experienced an increase in the duration of self-stimulatory behaviours, and all participants experienced an increase in the number of distractions and a

decrease in the duration of focused attention. The increase or decrease, however, never returned to baseline levels for these behaviours.

**Conclusion:** The findings suggest that for these five children with PDD, the use of a weighted vest resulted in an increase in attention to task and decrease in self-stimulatory behaviours. The most consistent improvements observed was the decreased number of distractions. Additional research is necessary to build consensus about the effectiveness of wearing a weighted vest to increase attention to task and decrease self-stimulatory behaviours for children with PDD.

Fertel-Daly, D., Bedell, G., & Hinojosa, J. (2001). Effects of a weighted vest on attention to task and self-stimulatory behaviours in preschoolers with pervasive developmental disorder. *American Journal of Occupational Therapy*, 55, 629-640.

**NOTE:** Deep pressure, a form of tactile sensory stimulation, is believed to have a calming effect on adults and children with pervasive developmental disorders (PDD). Temple Grandin ( a well published author with Autism Spectrum Disorder) has written about this extensively. The article in this edition written by **Geraldine Robertson** also mentions the effect of pressure on a young person with Autism Spectrum Disorder.

\*\*\*\*\* If you would like to read this entire article Autism Tasmania has a copy which you may access - just ring Rose Clark on 6423 1086.