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THE NEWSLETTER OF AUTISM TASMANIA INC.

Autism News

Welcome to the Mid Year Issue

This issue of Autism News contains a mixture of articles and I hope you find something that interests you. Sourcing articles and compiling the newsletter is a task that requires time and commitment, and I thank committee members for their efforts. A special thanks to Cheryl Scott, a former committee member, who continues to assist with this task.

Our library is finally operational and included with this issue is a list of books available for borrowing. Borrowing of books has taken many forms over the past 14 years, but we have not had a system that has enabled us to monitor and track the flow of books. Mick Clark has completed an audit of books which are now housed at "our office" at the Giant Steps Centre in Deloraine. Autism Tasmania is receiving regular donations of items from Footprint books also which are being reviewed by members and will then be added to the library. Watch future editions for reviews of outstanding new titles!

Also in this issue is advance notice of the Annual General Meeting to be held on 27th September and you are most welcome to attend. The meeting is kept short and includes presentation of the Financial report. I urge you to attend and support the organisation that supports you.

Please note the availability of the companion card in Tasmania - the website indicates that it can be used at Village cinemas and AFL games. This card will be welcome news for many families and as its success will depend on interest, please take advantage of this scheme.

Ros Ward - President



Wendy Lawson speaking to a group of interested members in Hobart recently. Photo by Peter hatters

Ten things every child with autism wishes you knew. By Ellen Notbohm

Some days it seems the only predictable thing about Autism is the unpredictability. The only consistent attribute is the inconsistency. There is little argument on any level, that autism is baffling, even to those who spend their lives around it. The child who lives with autism may look "normal" but his behavior can be perplexing and downright difficult.

Autism was once thought an "incurable" disorder, but that notion is crumbling in the face of knowledge and understanding that is increasing, even as you read this. Every day, individuals with autism are showing us that they can overcome, compensate for and otherwise manage many of autism's most challenging characteristics. Equipping those around our children with a simple understanding of autism's most basic elements has a tremendous impact on their ability to journey towards productive, independent adulthood.

Autism is an extremely complex disorder but for the purposes of this one article, we can distill its myriad characteristics into four fundamental areas: sensory processing challenges, speech/language delays and impairments, the elusive social interaction skills and whole child/self-esteem issues. And though these four elements may be common to many children, keep front-of-mind the fact that autism is a spectrum disorder: no two (or ten or twenty) children with autism will be completely alike. Every child will be at a different point on the spectrum. And, just as importantly – every parent, teacher and caregiver will be at a different point on the spectrum. Child or adult, each will have a unique set of needs.

Here are ten things every child with autism wishes you knew:

1. I am first and foremost a child. I have autism. I am not primarily "autistic." My autism is only one aspect of my total character. It does not define me as a person. Are you a person with thoughts, feelings and many talents, or are you just fat (overweight), myopic (wear glasses) or klutzy (uncoordinated, not good at sports)? Those may be things that I see first when I meet you, but they are not necessarily what you are all about.

As an adult, you have some control over how you define yourself. If you want to single out a single characteristic, you can make that known. As a child, I am still unfolding. Neither you nor I yet know what I may be capable of. Defining me by one characteristic runs the danger of setting up an expectation that may be too low. And if I get a sense that you don't think I "can do it," my natural response will be: Why try?

2. My sensory perceptions are disordered. Sensory integration may be the most difficult aspect of autism to understand, but it is arguably the most critical. This means that the ordinary sights, sounds, smells, tastes and touches of everyday that you may not even notice, can be downright painful for me. The very environment in which I have to live often seems hostile. I may appear withdrawn or belligerent to you but I am really just trying to defend myself. Here is why a "simple" trip to the grocery store may be hell for me:

My hearing may be hyper-acute. Dozens of people are talking at once. The loudspeaker booms today's special. Muzak whines from the sound system. Cash

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registers beep and cough, a coffee grinder is chugging. The meat cutter screeches, babies wail, carts creak, the fluorescent lighting hums. My brain can't filter all the input and I'm in overload!

My sense of smell may be highly sensitive. The fish at the meat counter isn't quite fresh, the guy standing next to us hasn't showered today, the deli is handing out sausage samples, the baby in line ahead of us has a poopy diaper, they're mopping up pickles on aisle 3 with ammonia....I can't sort it all out. I am dangerously nauseated.

Because I am visually oriented (see more on this below), this may be my first sense to become overstimulated. The fluorescent light is not only too bright, it buzzes and hums. The room seems to pulsate and it hurts my eyes. The pulsating light bounces off everything and distorts what I am seeing - - the space seems to be constantly changing. There's glare from windows, too many items for me to be able to focus (I may compensate with "tunnel vision"), moving fans on the ceiling, so many bodies in constant motion. All this affects my vestibular and proprioceptive senses, and now I can't even tell where my body is in space.

3. Please remember to distinguish between won't (I choose not to) and can't (I am not able to).

Receptive and expressive language and vocabulary can be major challenges for me. It isn't that I don't listen to instructions. It's that I can't understand you. When you call to me from across the room, this is what I hear: "*&^%\$#@, Billy. #\$\$^*&^%\$&*."

Instead, come speak directly to me in plain words: "Please put your book in your desk, Billy. It's time to go to lunch." This tells me what you want me to do

and what is going to happen next. Now it is much easier for me to comply.

4. I am a concrete thinker. This means I interpret language very literally. It's very confusing for me when you say, "Hold your horses, cowboy!" when what you really mean is "Please stop running." Don't tell me something is a "piece of cake" when there is no dessert in sight and what you really mean is "this will be easy for you to do." When you say "It's pouring cats and dogs," I see pets coming out of a pitcher. Please just tell me "It's raining very hard."

Idioms, puns, nuances, double entendres, inference, metaphors, allusions and sarcasm are lost on me.

5. Please be patient with my limited vocabulary. It's hard for me to tell you what I need when I don't know the words to describe my feelings. I may be hungry, frustrated, frightened or confused but right now those words are beyond my ability to express. Be alert for body language, withdrawal, agitation or other signs that something is wrong.

Or, there's a flip side to this: I may sound like a "little professor" or movie star, rattling off words or whole scripts well beyond my developmental age. These are messages I have memorized from the world around me to compensate for my language deficits because I know I am expected to respond when spoken to. They may come from books, TV, the speech of other people. It is called "echolalia." I don't necessarily understand the context or the terminology I'm using. I just know that it gets me off the hook for coming up with a reply.

6. Because language is so difficult for me, I am very visually oriented. Please show me how to do

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something rather than just telling me. And please be prepared to show me many times. Lots of consistent repetition helps me learn.

A visual schedule is extremely helpful as I move through my day. Like your day-timer, it relieves me of the stress of having to remember what comes next, makes for smooth transition between activities, helps me manage my time and meet your expectations. Here's a great website for learning more about visual schedules: www.cesa7.k12.wi.us/sped/autism/structure/str11.htm.

I won't lose the need for a visual schedule as I get older, but my "level of representation" may change. Before I can read, I need a visual schedule with photographs or simple drawings. As I get older, a combination of words and pictures may work, and later still, just words.

7. Please focus and build on what I can do rather than what I can't do. Like any other human, I can't learn in an environment where I'm constantly made to feel that I'm not good enough and that I need "fixing." Trying anything new when I am almost sure to be met with criticism, however "constructive," becomes something to be avoided. Look for my strengths and you will find them. There is more than one "right" way to do most things.

8. Please help me with social interactions. It may look like I don't want to play with the other kids on the playground, but sometimes it's just that I simply do not know how to start a conversation or enter a play situation. If you can encourage other children to invite me to join them at kickball or shooting baskets, it may be that I'm delighted to be included.

I do best in structured play activities that have a clear

beginning and end. I don't know how to "read" facial expressions, body language or the emotions of others, so I appreciate ongoing coaching in proper social responses. For example, if I laugh when Emily falls off the slide, it's not that I think it's funny. It's that I don't know the proper response. Teach me to say "Are you OK?"

9. Try to identify what triggers my meltdowns. Meltdowns, blow-ups, tantrums or whatever you want to call them are even more horrid for me than they are for you. They occur because one or more of my senses has gone into overload. If you can figure out why my meltdowns occur, they can be prevented. Keep a log noting times, settings, people, activities. A pattern may emerge.

Try to remember that all behavior is a form of communication. It tells you, when my words cannot, how I perceive something that is happening in my environment.

Parents, keep in mind as well: persistent behavior may have an underlying medical cause. Food allergies and sensitivities, sleep disorders and gastrointestinal problems can all have profound effects on behavior.

10. If you are a family member, please love me unconditionally. Banish thoughts like, "If he would just....." and "Why can't she....." You did not fulfill every last expectation your parents had for you and you wouldn't like being constantly reminded of it. I did not choose to have autism. But remember that it is happening to me, not you. Without your support, my chances of successful, self-reliant adulthood are slim. With your support and guidance, the possibilities are broader than you might think. I promise you – I am worth it.. And finally,

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three words: Patience. Patience. Patience. Work to view my autism as a different ability rather than a disability. Look past what you may see as limitations and see the gifts autism has given me. It may be true that I'm not good at eye contact or conversation, but have you noticed that I don't lie, cheat at games, tattle on my classmates or pass judgment on other people? Also true that I probably won't be the next Michael Jordan. But with my attention to fine detail and capacity for extraordinary focus, I might be the next Einstein. Or Mozart. Or Van Gogh.

They had autism too.

The answer to Alzheimer's, the enigma of extraterrestrial life -- what future achievements from today's children with autism, children like me, lie ahead?

All that I might become won't happen without you as

my foundation. Think through some of those societal 'rules' and if they don't make sense for me, let them go. Be my advocate, be my friend, and we'll see just how far I can go.



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Ellen Notbohm is author of **Ten Things Every Child with Autism Wishes You Knew**, a ForeWord 2005 Book of the Year Honorable Mention winner and recipient of iParenting's 2005 Media

Award. Her new book, **Ten Things Your Student with Autism Wishes You Knew** will be released in September 2006. She is co-author of **1001 Great Ideas for Teaching and Raising Children with Autism Spectrum Disorders**, winner of *Learning Magazine's* 2006 Teacher's Choice Award, and a columnist for *Autism Asperger's Digest* and *Children's Voice*. For article reprint permission, to learn more or to contact Ellen, please visit www.ellennotbohm.com

For your Diaries

AGM

The 14th Annual General Meeting of Autism Tasmania Inc will be held at 7.30pm on **Wednesday 27th September** at the Telehealth Studios of the

Launceston General Hospital,

the Royal Hobart Hospital and

the NW Regional Hospital. Burnie Campus

Other Telehealth locations and phone lines can be arranged

on request to the Secretary (Mick Clark)

The Formal Notice of Meeting will be sent to all financial members

by mail or email in early September

Bullying and Autism Spectrum Disorder reprinted from 'The Spectrum' Autumn 2006 by Kristy Kerr of Autism Victoria

Community awareness and understanding of bullying behaviour has improved in recent years.

Nevertheless, students with an Autism Spectrum Disorder remain highly vulnerable to bullying behaviour, and parents, teachers, other students and the community must become sensitive to the particular needs of these students

Protecting the student with Autism Spectrum Disorder from bullying behaviour at school

Occasionally we receive calls from parents who are concerned about their child being bullied at school. The majority are parents of children with high-functioning autism or Asperger Syndrome, attending mainstream schools. British statistics suggest that students with special education needs attending a mainstream setting are three times more likely than their age peers to be bullied'.

How can you tell if your child has been bullied? What characteristics make students with Autism Spectrum Disorder the target of bullying? What can parents, teachers and peers do to prevent bullying, and keep the student with Autism Spectrum Disorder happy and safe?

Identifying that your child is being bullied

Your child may be able to tell you when something happened at school that made them unhappy, or you may notice injuries such as bruises or scratches, torn clothing or missing items². Alternatively, changes in your child's behaviour may alert you to the possibility of bullying.

A child who is being bullied may have difficulties with eating or sleeping (which were not previously present), have nightmares with the theme of being verbally or physically hurt, or refuse to go to school. There are other reasons for such behaviour, so it is important to do some further investigation with the child. A direct (but leading) way is to simply ask the child if anyone has made them sad. Parents may wish to use a less direct (and neutral) approach by use of an emotions timeline with their child. This lists routines of the day in chronological order. The child is given pictures of happy, sad and angry. The parent starts at the beginning of the day and says the name of the

activity (for example, recess) and the child selects the correct face to represent the feeling at that time. If the child selects sad or angry, the parent tries to elicit the events occurring and how it has led to that emotion. If bullying is not identified, then an idea of the reasons for such behaviour change may be found.

Parents may like to casually speak to the teacher about whether they can identify any upsetting aspects of school for the child. Parents may also want to speak to classmates they are familiar with, to determine if these children have witnessed any incidents of teasing or hurting towards their child.

For example, "I'm worried about _____. He has been sad lately. Have you noticed anyone saying unfriendly things, or doing things to hurt him? "

Older children may wish to use a 'grievance book'³ (as described by Tony Attwood) to record incidents that have bothered them (potentially bullying incidents). This can also be used later as a chronological record of bullying incidents, if these occur over time, in order to share with the child's school when addressing the issue. **'The Modified Inventory of Wrongful Activities'**⁴ is a questionnaire suitable for secondary school aged children to complete, in order to elicit information about the types of bullying incidents occurring. Parents may wish to read this and use the questions as the basis of a discussion with their child.

What makes a child with Autism Spectrum Disorder susceptible to bullying?

The following characteristics of the child with Autism Spectrum Disorder may lead them to be the target of bullies.

1. Other students may notice the unique mannerisms of the child, such as pacing, verbalising thoughts out loud, or repetitive body movements, and pick on this difference.

Strategy: Teach more acceptable alternatives¹, such as:

- pacing round the oval, so it looks like the child is exercising.

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- speaking quietly to themselves (or 'think it, don't say it')
- completing hand movements under the table twirling a school related item like blu-tac or a pencil in their hand, or fiddling with a bracelet instead of flapping hands, or
- educating other students that these mannerisms are a sign that the student with an Autism Spectrum Disorder is not coping, and that they should offer help, or find a teacher to provide help.

2. Many students with Autism Spectrum Disorder prefer solitary play, or find it hard to socialise successfully with peers. Bullies may recognise that the child is vulnerable without close peers to protect them.

Strategies could include:

- fostering the child's friendships by arranging some play dates after school and providing the child the support necessary for the play date to be successful,
- teaching the child simple games, suitable for their age such as chasey, as this enables the child to join with others in a structured and predictable game,
- asking the school to provide specific equipment for familiar games at recess so the child knows what to play, and how to join others, and
- teaching the child to play near a large group, even if not joining in, as a way to be 'seen by many', and therefore be safer in a crowd.

3. The child's sensitivity may make their reactions to provocation seem comical to bullies. The child may become teary or angry quite easily after being taunted, and so this is an instant pay-off for the bully trying to get a reaction. This is particularly so for those with Asperger Syndrome.

Strategy: Develop a bullying shield with the child. This is a concrete and visual way to represent protective thoughts for the child. The shield can be as simple as a sheet of paper, or complex as whatever model the child wants to make. An adult helps the child come up with some statements to counter what is being said to them (for example, the bully says 'you smell', and the child's statement could be 'I smell like flowers' or 'I wash every day so I smell pleasant'). The agreed to statement is written on the shield. The child

is prompted to think of the shield when being bullied - and of the bully's statements bouncing off the shield. This is not necessarily so they can say their counter-statement, but more so they can see that the taunt is not true, and so remain calm. Some children like to visualise putting on a raincoat as a barrier to teasing words instead of using a more abstract 'shield'.

4. The child who has difficulties with generalisation may repeat a mistake from a previous occasion, retriggering the bully's humiliation of them. Luke Jackson, author of *Freaks, Geeks and Asperger Syndrome* recounts how he would go to the same place each day where the bullies were, not modifying his behaviour from the last time they had taunted him.

When he did seek to change this pattern, he went to secluded places in the school ground, thinking he was hiding from the bullies, but really making himself vulnerable to attack without witnesses or other people to intervene.

Strategy: The school may provide a safe place inside to go if needed, such as a supervised indoor activity. If this is not possible, teach the student who plays in the yard where he can play in plain view of other students and staff. If incidents occur within the line of sight of duty teachers or the staffroom, teachers are more likely to see, and respond to an incident.

5. The child may not recognise the intent behind the bullying behaviour and may actually think the bully is being friendly. Carol Gray² highlights an example where a child was asked to 'shake hands' with another child, then pushed to the ground and hit.

Strategy: Teach the child how to recognise suspicious or unfriendly behaviour. In general, shaking hands is an adult activity, so children should be suspicious of another child offering this.

Similarly, a child offering to be friends if given money is not a real friend - teach the child that friendship does not need to be paid for. Similarly teach the child that a real friend doesn't ask you to do something that would hurt yourself or someone else.

A child's literal interpretation of language may set them up for further teasing (for example, showing unusual approaches to join a group, and being told 'go away'. The child may then genuinely question 'go where?')

Strategy: If a child recounts an incident such as this, correct their confusion by providing a concrete example: *"when a child says 'go away', they really mean 'go away from me', and you should move to a different area where people look more friendly. If you can't find friendly students - go to the duty teacher and ask for help.*

Many of the above strategies have suggested ways to increase the child's abilities and skills. This is not to say that their difficulties are to blame for the bullying, rather that even the most caring teachers may not see the bullying incidents as they occur. In that case, the most immediate way to help the child is to equip them with the means to prevent some bullying incidents. Of course the best way to stamp out bullying altogether is to deter bullies, catch them out if they persist, and then provide appropriate punishment (see more suggestions for teachers below).

More strategies to help the child who is being bullied

For Parents

Know the school's bullying policy, and use this information to your advantage. Every school is required to have a bullying policy, and some sample policies can be found in the Department of Education 'Addressing Bullying Behaviour in Schools: Resource Booklet' at www.sofweb.vic.edu.au/bullying.

Meet with the school to discuss incidents, how these were handled, and whether this is in accordance with the school's policy. If you have a good relationship with the class teacher, begin by talking with them. For more serious matters, such as physical violence against your child, or ongoing teasing, requesting a meeting in writing through the principal is suggested. For such a meeting, making a list of the issues to cover, and bringing along documentation of the events over time (see reference to the 'grievance book' above) can help keep the meeting on track. Ask your partner or a friend to come to the meeting as a support person if you feel overwhelmed speaking to the teacher and principal by yourself.

If a resolution of grievances cannot be achieved to your satisfaction at teacher or principal level, parents can then contact the Education Department's Disability and Student Welfare Section in their region OR the Student Wellbeing Branch at Head Office.

For Teachers:

Lead by example. Show in your attitude and actions that bullying behaviour is not tolerated by you. Address every incident you witness or hear about. Don't turn a blind eye, thinking that the students involved should just sort things out themselves. Although this may work for other students, the student with Autism Spectrum Disorder does not have the social understanding, or perspective-taking ability to do this. They will need education about what went wrong, and why. They will also need a clear guideline about what to do next time to try to avoid the same situation reoccurring.

Incorporate specific bullying training into the curriculum, such as information about how to recognise bullying. Use Carol Gray's '**How to respond to a bullying attempt**'⁶ to set up teams amongst classmates who will then watch out for each other in the playground. This method also teaches children exactly what to say and do when they are faced with bullying behaviour.

Other preventative measures, like a 'buddy system', or a 'circle of friends' can help the student with Autism Spectrum Disorder be included in a group of students who look out for them in the playground. Although this takes time to set up, it can save time for duty teachers later on if they are not dealing with bullying incidents, and therefore is a good investment.

Choose carefully when assigning an older buddy or when inviting potential members into a circle of friends as there is the potential for bullying within these programs!

Highlight pro-social, inclusive and caring actions by classmates as a model of how to treat others. Reward such behaviour with your overt approval.

Provide consequences for bystanders. One way to stop bullying going unnoticed is to treat bystanders as if they are as guilty as the bullies. This then gives students the choice to stay on witnessing and possibly encouraging the bullying, or to leave, providing less of an audience, and going to seek teacher intervention.

Many more suggestions about how to tackle bullying at a class level can be found in '**Perfect Targets: Asperger Syndrome and Bullying**' by Rebekah Heinrichs⁴

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Other Issues

Perceived bullying. Sometimes the student with Autism Spectrum Disorder will misinterpret an unintentional bump in line as purposeful physical aggression, and retaliate. At other times, the student may misinterpret good-natured teasing or 'banter- aimed at including them (see also 'what if my child is the bully?' below). For example, peers may say to the student 'How's it hanging?', meaning 'How are you?'. The student with Autism Spectrum Disorder may misinterpret this as somehow an insult about their being droopy. Another example is where teen boys use phrases borrowed from American gang speak, such as 'dog/dawg' meaning 'homeboy' or 'friend'. The teen with Autism Spectrum Disorder may interpret this literally, and feel insulted that they are being likened to an animal.

When the student with Autism Spectrum Disorder reports that they are being teased, it is therefore important to determine exactly what words were said to them. Then teachers and parents need to learn more about the terms that teenagers use, and demystify these for the student with an Autism Spectrum Disorder. Brenda Boyd offers some guidelines for assessing a child's level of understanding in relation to bullying, banter and teasing, and unintentional hurting in her book '**Parenting a child with Asperger Syndrome**'⁸.

What if my child with Autism Spectrum Disorder is the bully?

If it has been reported to you that your child has been the perpetrator of bullying, it is important to establish exactly what happened during the incident (that is, everything that was done and said). It can then be determined why your child is responding in this way, and teach alternative responses. Reasons for bullying may include:

- retaliating for perceived purposeful bumping,
- retaliating for perceived insults,
- sensory overload and lashing out,
- learning that bullying is a way to be left alone⁹,
- not recognising the emotional effect on others,
- being set up by other classmates¹, and
- attempts to be part of a group of other children who are bullies.¹

Comic strip conversations are a useful tool¹⁰. Developed by Carol Gray, comic strip conversations are a way to visually and concretely represent a situation that has occurred, such as the incident where another student felt the student with Autism Spectrum Disorder was bullying them. Stick figures are drawn to represent each person involved, and speech bubbles show what each person said. Thought bubbles are then included to show what each person thought or was feeling. Misunderstandings can be identified and the student with Autism Spectrum Disorder can be helped to gain insight into how the other person was affected by their actions. Traditional punishments will not be effective in changing their bullying behaviour unless the student understands why the behaviour was not appropriate, and what they should do instead the next time a similar situation occurs.

What if the teacher is the bully?

Often when disciplining a student, the teacher will reprimand them in front of the class. This works well with most students - they are sufficiently embarrassed that they will not repeat the undesirable behaviour again. The student with Autism Spectrum Disorder may not have the desire to please the teacher, and such a reprimand may serve to confuse them. The child may realise they are in trouble, but not understand what they need to change in order to put things right. Consider the following excerpt from the book '**Blue Bottle Mystery**'¹¹ where the main character, Ben, who has Asperger Syndrome is reprimanded by his teacher.

..... "Listen son". Miss Browning-Lever said in a hard voice, "I'm sick of your attitude. When you will speak to me, you will address me as Miss Browning Lever, understand?". Ben felt sick. What did 'address her' mean? He didn't understand any of this conversation. He didn 't know why he was in trouble. How he hated school!.

The student with Autism Spectrum Disorder can appear to be defiant and provocative at times if they do not understand what is expected, if they correct the teacher in a pedantic manner, or if they interpret literally what the teacher has said. A teacher unfamiliar with the characteristics of Autism Spectrum Disorder may repeatedly reprimand a child in the manner above, wondering why the child just won't do as they are told and leading the child to fear them as they would a bully.

Strategies: Ensure the teacher knows about Autism Spectrum Disorder, and how this may affect the

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student's behaviour and level of comprehension. Most teachers who are informed will try to be sensitive to the student's needs. A comic strip conversation⁹ can help a teacher understand which parts of an interaction the child misunderstood, and how both can avoid the same situation occurring. If the child continues to feel distressed about a teacher's response to them, utilise the suggestions for parents in the 'more strategies to help the child who is being bullied' section above.

Bullying in Specialist School Settings

Calls to Autism Victoria for advice about bullying are rarely from parents of a child in a specialist school setting (SDS, Special School or autism specific school). This may be because the other students, due to their own difficulties are not aware of the child's differences, and therefore teasing does not occur. Alternatively it may be that children attending these settings are less able to report bullying to us. If behaviour change indicative of bullying is apparent in the child (as described at the start of this article), investigate further with the child's school staff and enlist their help to increase supervision at those times where bullying may be occurring.

Bullying Bibliography

All references used in compiling this article are available for loan from the Autism Victoria library (the accession number # is in brackets):

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3. Attwood, T. **Asperger Syndrome: A guide for parents and professionals** (#1560)
4. Heinrichs, R. **Perfect Targets** (#2436)
5. Jackson, L. **Freaks, Geeks and Asperger Syndrome** (#2252)
6. Gray, C. **How to respond to a bullying attempt.** (#1992 discussion of method and examples for implementation and #1993 workbook for children)
7. Victorian Parent Advocacy Collective. **Circles of Friends** - video and manual (#1375)
8. Boyd, B. **Parenting a Child with Asperger Syndrome.** (#2402)
9. Attwood, T. **Asperger Syndrome Part Two DVD** (section on anger) (#269)
10. Gray, C. **Comic Strip Conversations** (#1912)
11. Hoopman, K. **Blue Bottle Mystery** (#2013)

Board game: Searle and Strengh. **The Anti Bullying Game.** (#2687)

Carter, M and Santomauro, J. Social Spectrum, Bullying issue (#2677)

Kirsty Kerr, the Autism Victoria Family Counsellor, prepared the material above. A reprint of this article is available from the Autism Victoria office. All books mentioned are available for loan from the Autism Victoria library.

New Companion Card for Tasmania

The new **Companion Card** is for for people with a disability.

The aim of the Card is to enable people who require someone to support them, when accessing a function in the community (eg a show, concert, festival etc) to show their card and receive free access for their support person to participating organisations or venues. This scheme is organised through the Premiers Dept.

To register for the Card, please phone 1800 009 501 or email disability@dpac.tas.gov.au

Obviously the more people who register for a Card the more successful the program will be.

Information on Companions card can be found at www.vic.companioncard.org.au/cc/ccabout.htm

If there is a venue or activity eg AGFEST CMax etc that you would like to be included on the program, you should email disability@dpac.tas.gov.au to ensure that what interests your child or the person you are caring for, can be included.

Autism 'more common than thought'

Autism, and similar disorders, may affect up to one in 100 children, UK researchers have suggested.

The figures suggest the condition is more common, as prior to the 1990s, experts said there were four to five cases per 10,000 people in Britain.

Researchers said it was unclear whether their higher estimate was due to better diagnosis or increased incidence.

Experts said the study showed services for people with autism spectrum disorders (ASDs) had to be improved.

Autism impairs social interaction, communication, and imagination. The spectrum also covers Asperger's syndrome.

Service boost needed

Researchers from Guy's and St Thomas' Hospital in south London, publishing their findings in the *Lancet*, looked at a group of 57,000 children aged nine and 10 in 2001.

They identified 255 who had already been diagnosed as having autistic disorders and 1,515 judged to be possible undetected cases.

A randomly selected sub-group of 255 children was chosen for in-depth clinical assessment.

The prevalence of "classic" childhood autism was 39 per 10,000, and that of other ASDs 77 per 10,000.

In total, autistic disorders affected 116 per 10,000 children.

The researchers extrapolated their findings to suggest one in 100 British children may have some form of autism.

Professor Gillian Baird, who led the research, said: "Prevalence of autism and related ASDs is substantially higher than previously recognised.

"Whether the increase is due to better ascertainment, broadening diagnostic criteria, or increased incidence is unclear.

"Services in health, education, and social care will need to recognise the needs of children with some form of ASD, who constitute 1% of the child population."

Autism 'no longer rare'

But experts said there was no evidence to link the increase in cases to the measles, mumps and rubella jab or thimerosal, a vaccine preservative which uses mercury.

An editorial in the *Lancet* by Dr Hiroshi Kurita of Tokyo's Zenkoku Ryoiku Sodan Centre says there has been a continued incidence of ASDs after MMR was withdrawn in a district of Yokohama City in Japan and in Denmark, where thimerosal was taken out of vaccines.

Professor Simon Baron Cohen, of the Autism Research Centre in Cambridge, said: "This new study establishes that autism spectrum conditions are no longer rare.

"Service planning is needed to adjust to these new prevalence rates, so that the education, health, and related systems can meet the needs of people on the autistic spectrum."

The National Autistic Society (NAS) said the study's findings fitted in with its own estimates of the incidence of ASD - and the need for improved services - but it was unclear why more cases were being seen.

The NAS said its helpline received 35,600 calls last year from individuals with autism and their families, many of whom were unable to access the services they require.

Mike Collins, NAS head of Education, said: "Current provision for those with the disability is deeply inadequate given the scale of the need.

"Government and local authorities must ensure that education, health and social services are adequately funded and all staff appropriately trained in order to meet the needs of those living with the disability and their families.

"Autism is a lifelong disability and when an individual's needs are not met the long term consequences both financially and for the individual's well being are profound."

News and Views in the Autism Community

Apex Trust for Autism Grant Call

Applications for these small but important autism-specific research grants for 2006/07 closed on 31 July 2006. The long-standing collaboration between the Apex Foundation [through their Trust for Autism] and the Autism Council of Australia [ACA] assumes special significance this year as Apex across Australia celebrates 75 years of selfless community work and the Foundation, it's 30th anniversary. Autism Victoria's Executive Officer, Amanda Golding coordinates the grant application process for Apex and the ACA. Grants will be assessed over the next few months by the ACA's Professional Committee chaired by Dr Verity Bottroff. Tasmania's Professional Committee member, Sue Brown will be involved in this process.

\$12,000 was available for disbursement in 2005/06, including a \$5,000 contribution directly from the ACA, with thanks to Gaffney International's 'Thomas & Friends' donation to Australian autism research. Successful 2005/06 grant recipients – selected from 10 applications – were:

Dr Umesh Sharma, Faculty of Education, Monash University - \$5,589

Empowering parents of children with Autism to manage disruptive behaviours

Dr Robyn Young, School of Psychology, Flinders University - \$6,411

A two-year follow-up of the children of the University's Early Intervention Research Program

The Flinders University Early Intervention Research Program [EIRP] provides intensive early intervention to children with an ASD or those considered at risk between 1 and 5 years of age. The Program involves some children as young as 18 months, whose diagnoses have previously been

difficult to support and targets early behaviours, recently identified and considered linked to autism's core neurological deficits [Young, Brewer & Pattison, 2003]. With an initial grant from the Apex Foundation, these behaviours were operationalised and now form the basis of an early screening tool called the Flinders Observational Schedule of Pre-Autistic Characteristics [FOSPAC]. The tool is currently being reviewed for publication.

Over 130 children commenced the original program. All were assessed on four occasions – 2 weeks prior to intervention; immediately before intervention; 2 weeks following intensive intervention on campus; and 20 weeks after finishing the home-based component of the program. Overall, children have demonstrated significant improvements in the severity of their disorder, as well as behaviours specifically targeted by the EIRP such as joint attention, eye contact, functional play, pretend play and imitation and response to verbal commands.

The current grant enables a follow-up of some of the children who completed the program over 2 years ago. The specific interest is in outcome variables such as autism severity, language and social skills and general adaptive functioning, as well as learning how many of these children are now attending main-stream schooling and what level of support is required.

[Acknowledgement to 'Apex in Action' newsletter, May 2006 for part of this article]

Autism Prevalence Study in Final Stages

This study - initiated by the Autism Council of Australia (ACA) with a \$50,000 research grant from the Australian Government through [the now] FaCSIA - has been in progress since March 2005. With Australia-wide data collection completed, the final stage entailing a statistical and descriptive analysis of the data is underway. A final draft report is expected in

September 2006, for release later in the year.

The project is being undertaken by a research team led by Dr John Wray, FRACP, Paediatrician, Head of Department, State Child Development Centre, Perth, WA, with Dr Emma Glasson, PhD, Research Fellow, Telethon Institute of Child Health Research, Perth, WA; Dr Katrina Williams, PhD, FRACP, FAFPHM, Paediatric Epidemiologist, Westmead Children's Hospital, Sydney, NSW; and Project Officers Danielle Wheeler, BSc; Greta Ridley, PhD; and Sarah MacDermott, MA.

The goals of the study are to identify, as accurately as possible:

1. The number of Australian children, aged from birth to 16 years of age, who have a formal diagnosis of Autism Spectrum Disorder. This would include Autism Disorder, Asperger's Syndrome or Pervasive Development Disorder – Not Otherwise Specified (PDD-NOS).
2. Additional information regarding this group of children which will assist in the development of a broader picture of their needs, such as gender, ethnicity, residential location (metropolitan compared with rural/remote), developmental needs and interventions accessed.
3. Information about the diagnosis, such as who provided it (what professionals and if they worked individually or as part of a team) and what criteria were used in the assessment.
4. Who funds and who provides both diagnostic and intervention services in each of the states/territories?

The study is the first opportunity to develop a national overview of the numbers and distribution of children with an Autism Spectrum Disorder across Australia and to start to build a national picture of the needs of this population in terms of access to both diagnostic and intervention services.

Autism Community Mourns Loss of Dr. Eric Schopler

The autism community worldwide was deeply saddened to learn of the death of Dr Eric Schopler, M.D., from cancer, in early July. Schopler - an honorary board member of the Autism Society of America - revolutionized treatment for children and adults with autism through an extraordinary career. Upon joining the faculty of the University of North Carolina at Chapel Hill in 1964, he replaced psychodynamic theories of "parent blaming" with parent-professional collaboration and provision of the best possible educational opportunities to children with autism. Dr Schopler initiated the TEACCH Program's humane, innovative approach to autism at a time when the field was quite primitive, and his work has influenced autism treatment worldwide. In addition, his scholarly activities have enriched the field and disseminated his forward-thinking ideas to programs everywhere.

"Mozart and the Whale"

A movie featuring predominantly characters with Asperger Syndrome – this summary is courtesy of Amanda Golding [Executive Officer, Autism Victoria], who has been tracking the progress of this movie for a couple of years. The writer has used the 'story' of Jerry and Mary Newport to create this movie. It had limited release in the US, and did not get released in Australia at all, even though Radha Mitchell, an Aussie actress, has a lead role. It has just been released on DVD and several of the video chains have a limited number of copies. Now that Wimbledon and the World Cup are over, we can reclaim our television sets and catch up on the latest movies!

"Mozart and the Whale" is well worth watching. It is a fairly simple story line, tagged 'romantic comedy-drama' with an M rating. But the characterisations are intriguing, respectful and very realistic. Josh Hartnett in the lead role is excellent. He has captured the many nuances of Asperger Syndrome in a sincere and sympathetic way. There will be debate about whether some of the

(Continued from page 13)

movie's characters have Aspergers or Autism, but what struck me is that each character is treated as an individual, and when viewed collectively, illustrates very well the breadth of the spectrum. The extra "Behind the Scenes" story on the DVD is very informative and features Jerry Newport, who was advisor to the director and cast.

The friendship experiences of children with an Autism Spectrum Disorder

Although we know that friendships play a very important role in typical children's development, we know very little about the role that friendships play in the lives of children with an Autism Spectrum Disorder. A new study is underway at RMIT University that is examining the friendships and emotional wellbeing of children with an Autism Spectrum Disorder. If you are the parent of a child with an Autism Spectrum Disorder and your child is aged between 10 and 17 years, your participation in this study would be greatly appreciated.

We are interested in finding out about your child's current friendships, your child's level of interest in friendships, and your child's emotional wellbeing. If you would like to

participate, you will be asked to complete questionnaires that will take approximately 45 minutes to complete. The questionnaires are entirely confidential. We will provide you with a summary of the study results upon completion of the project. The findings of this study will improve our understanding of the impact the friendships have upon the emotional wellbeing of children with an Autism Spectrum Disorder. This information can then be used to develop informed interventions, to improve the friendships and emotional wellbeing of these children.

If you would like further information, or would like to register your interest in participating in the study, please contact:

Katelyn Moore

Doctor of Psychology student

s3041651@student.rmit.edu.au

ph: 0421 854 100

OR

Dr Amanda Richdale

Research Supervisor

amanda.richdale@rmit.edu.au

ph: 9925 7366

Overview of the Commonwealth Government's Welfare to Work Package - by Peter Hatters

From the 1st of July 2006 the Commonwealth Government initiated the new Welfare to Work Program targeting people with disabilities. Australia currently has over 700,000 people receiving Disability Support Pensions (DSP). The Government would like to provide more people with the opportunity of making a contribution through employment. The Welfare to Work reforms will focus on four priority groups: people with disabilities, principal carer parents of children over the age of 6, mature age job seekers (50 or over) and people who have been unemployed for a long time.

From 1 July 2006, people who are assessed as capable of working 15-29 hours per week will have to look for work

if receiving a government benefit. Depending on a person's individual needs, people will have access to Specialist Disability Services, Vocational Rehabilitation, Australian Apprenticeships, Job Search and placement help, and/or ongoing workplace support.

The new changes will not affect people who were on a Disability Support Pension before 10 May 2005. However, people currently claiming the Disability Support Pension who are having their DSP reviewed, may be referred to a Job Capacity Assessor to determine if they can work for a minimum of 15 hours per week.

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A Job Capacity Assessment (JCA) identifies a person's ability to work and any barriers that may prevent them from getting and/or keeping a job. This assessment will determine the most appropriate service to suit the job seeker and refer them directly to the relevant employment assistance agency or support service. The assessment will generally take about 45 minutes.

Prior to July 1 2006 Centrelink was the main referral point for people with a disability. Centrelink would carry out an assessment and determine what benefit a person should be on, and what service, if required, would meet their needs. Centrelink will continue to do this as they are a Job Capacity Assessor along with CRS and some private providers. The Job Capacity Assessor will now play a key role in supporting people getting into work. Of the 2.5 million Australians of workforce age (15-64 years) receiving

income support as at March 2006, only about 15 per cent had a requirement to look for work. This has resulted in a high rate of welfare dependence despite a relatively low unemployment rate. The Australian Government considers that the best form of income comes from a job rather than welfare, though there should also be a safety net for those who need it. For people with an ASD and their carers, this will have impact under the new guidelines. People with disabilities may be obliged to make regular contact with their service provider, as some people will be activity tested. People with an ASD or their carer who fail to meet their Activity Agreement, could have their benefit suspended for 8 weeks. If a benefit is the primary source of income for people, this may place significant pressure on their ability to live to their normal lifestyle.

For further details contact your local Centrelink office.

Peter Hatters

The 2007 Biennial Australian Conference on Autism Spectrum Disorders.

The event will be held from 14 – 16 March 2007 at the Royal Pines Resort, Gold Coast and is hosted and organised by Autism Queensland Inc under the auspices of the Autism Council of Australia. The theme of the conference – *Creative Futures* – incites energy, creativity and vision in research and services supporting the lives of people living with ASD and their families. This conference is for people with an ASD, their friends and families, researchers, clinicians, professionals and others with an interest in enhancing the lives of people living with an ASD. Keynote Speakers are:

Professor Catherine Lord

Professor of Psychology, University of Michigan, USA
Director of the Autism Center at the University of Michigan

Professor Rita Jordan

Director, Autism & Communication Disorders Center, UK
Professor, Psychology, College of Literature, Science & the Arts, Professor, Psychiatry

Dr Lorna Wing MD FRCPsych

Founder, National Autistic Society UK
Consultant Psychiatrist NAS Centre for Social & Communication Disorders

Dr Tony Attwood Psychologist

The Call for Papers closes on 14th September and intending presenters will be notified by the 30 September after this. The full conference program will then follow in due course.

Keep up to date with the full conference details - go to www.autismqld.com.au or use the link from the ACA website at www.autismaus.org.au or from September, the Autism Tasmania website at www.autismtas.org.au Telephone information is available from Autism Queensland on 07 3273 0000 or by fax on 07 3273 8306.



The 2007 Biennial Australian Conference on
Autism Spectrum Disorders



THE NEWSLETTER OF
AUTISM TASMANIA
INC.

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*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

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Autism Tasmania 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 3rd according to 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.)

Cygnnet /Huonville - meetings as requested by parents – either in Cygnnet or Huonville.

North

North – Notices will be sent out.

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 and East Coasts

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

Sheffield – details of meetings will be sent out

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

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

These groups have been established at the wish of parents who attend them. At times, depending on interest Speakers are invited to share information. At other sessions, parents swap ideas/strategies/information about services and issues relating to Autism.

PLEASE NOTE: Dates and locations can change due to a guest speakers availability. For further information and details give Rose a ring on 6423 2288 or 0407 320 048