

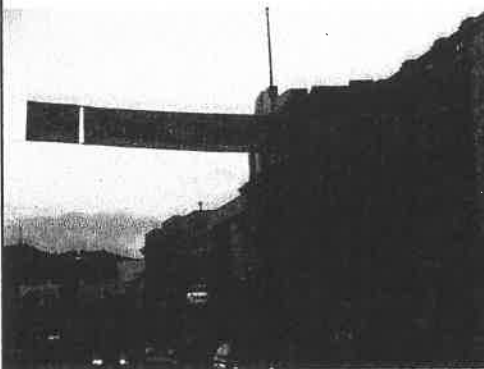


AUTISM AWARENESS WEEK 2004

National Autism Awareness Week was held recently and Autism Tasmania again hosted a variety of activities throughout the state.

Community displays were erected in the libraries at Glenorchy, Bridgewater, Launceston, Devonport & Burnie, as well as the Devonport Community Health Centre.

Autism Tasmania and ABIT shared the costs of printing and hanging a large banner, promoting Autism Awareness, across Collins Street in Hobart. Feedback was positive and it is intended to use the banner elsewhere in the state next year.



One of our major fundraisers for the year, a Charity Collection Day, was held on Friday 15th May, and we thank those people who gave up their time to help raise funds.

The Gold Coin program, included with the last bulletin, was an addition to our fundraising and had the added incentive of earning members a years free membership. Again we thank those members who sought out friends and workmates for this venture. In the meantime, remember to send in your completed Gold Coin Collection sheets to be in the running for a free membership for 2005. Winners

will be notified by mail. We hope that this activity will develop into another strong aspect of National Autism Awareness Week.

Members may also have seen the Community Service announcements on Southern Cross utilising some of the faces painted by Hocus Pocus face painters last year.

Under the theme of "Face Autism", face painting was again held throughout the state. Some wonderful faces appeared in the media, with colour photos featuring in the Advocate and Examiner, highlighting autism week. Many "celebrities" supported this activity, including state politicians Kathryn Hay, Sue Napier and Kerry Finch.

The East Coast was not left out this year; local member, Karen

(Continued on page 2)

Inside this Issue:

Autism Awareness Week 2004	1
Leisure Time	2
Interventions in Autism	3
Changing the future for Adults with Autism	6
Making smarter use of medications for Autism	8
Breakthrough in understanding the development of the Autistic brain	11
About Carers	13
Autism and AAC	15
The Family Support Coordinator role explained	16

(Continued from page 1)

Rawnsley ran a very successful community event.

Radio coverage included an interview with Vice President, Penny Cromarty and Karen Rawnsley on the ABC which went statewide and Rose Clark did an interview with Mal Gavin at Heart FM. Autism was also mentioned on Wendy Kennedy's "Tasmania Today" radio show and ABIT also

organised an article featuring Jeremy Geard in the Mercury in Southern Tasmania.

Mick Clark was the convenor of Autism Week activities and is keen to build on the strengths of this year for 2005. A meeting is being planned for July with all interested persons to develop these activities further. Stay tuned for details!

LEISURE TIME - reprinted from Autism News (WA) Sept 2003

For many families, occupying the child with Autism for a time without their need for an adult "on tap" is a major challenge. Many carers report that one of the most tiring and stressful aspects of caring is that their child cannot occupy him/herself without constant prompting or direction. Although there is no magic answer to this problem, there are some strategies that can help. In addition, teaching the child to be able to play independently while they are young, avoids the more difficult problem of trying to change the ingrained habits of an adult.

Find things the child enjoys doing

This is not always easy, but take notice of the activities that the child seems to enjoy most and use those as a starting point. These activities may be incorporated into the child's independent play time or other activities related to these may be developed. Also keep exploring a variety of activities for those that may be able to be adapted for your child.

Accept what the individual likes

What we are discussing here are leisure activities. Their dual functions are to provide the individual with enjoyment and to give the carer a break. These activities do not have to be "constructive" or educational. Nor do they necessarily have to be age appropriate. The criteria are that the individual enjoys them, that they can do them independently and that they are not harmful. If the child enjoys watching "his" video for the five thousandth time, let him and don't stress about your decision. Obviously, we are not suggesting that he should spend all his time doing these things. Instead we are saying that there is a need to make the distinction between skill development time and

recreation. In other words, it is important that the individual and the carer have some "down time" ie. that you both have a break. During this time, the individual should be able to pursue whatever activities will keep him happily occupied. Activities a child enjoys can be broadened into more complex, longer lasting activities if necessary. For example, a child who loves to sift through sand can gradually develop a more complex routine involving sifting through sand to find pieces of Lego hidden in it and then assembling these into a pattern..

Developing New Skills: Be prepared to spend time to get time. When first developing new play skills, it may be necessary to spend some time finding enjoyable activities, developing materials or systems (such as activity schedules) in order to teach the person new skills. However, this time will pay off, if the person becomes able to occupy themselves for substantial periods without needing constant attention. Remember in your teaching, however, that this is play, not work. If the teaching sessions are too demanding, the individual will not be likely to pursue the activity independently later. Remember, keep it light hearted and have fun. You want to create a pleasant association with the activities you are training.

Start small

If the individual has not been used to playing independently, don't expect them to suddenly start being independent for long periods. Even a couple of minutes in the beginning is a good start. However, with the development of skill, and the pairing of this activity with positive attention, then you can expect the time spent in these new

(Continued on page 3)

(Continued from page 2)

activities to gradually occupy longer times. Remember Rome wasn't built in a day. One of the biggest reasons for failure is where your expectations of what you and your child can achieve in the early stages are too high.

Use activity schedules

The book, *Activity Schedules* by Lynne McClannahan and Patricia Krantz provides a very detailed account of how to use these supports. Briefly, they provide the individual with a system of visual prompts to cue them to complete a range of leisure activities.

Use this time to have a break

It may be that for you, the most relaxing thing to do is to cook dinner without having to constantly supervise the child with Autism. If so, cook away. However, if this is not the case, this is a good time to actually have a break. Remember a major reason for teaching the person to be more independent is so that the carer can catch his/her breath.

Reprinted with permission from the Autism Association of WA

Interventions in Autism by Professor Pat Howlin

Pat Howlin is the Professor of Clinical Psychology, St Georges Hospital Medical School, London. Pat is a Consultant Chartered Clinical Psychologist, and has been involved in research and clinical work with people with autism and their families for many years. Her recent research studies have examined home based treatment programs; follow up into adult life; teaching Theory of Mind and the effectiveness of supported employment schemes. Prior to visiting Tasmania, Pat spoke to a large group in Melbourne. Here is an outline of her presentation which was also given to an enthusiastic group in Launceston.

Incidence.

Is there an increase in the incidence of autism? There is no doubt that there is an increase in the prevalence, or actual number of cases of Autism Spectrum Disorder being diagnosed. Most studies are based on prevalence figures, and their findings are being used to estimate the incidence of Autism Spectrum Disorder in the population. Hence the estimated incidence has increased from 2-5 per 10,000 (first cited in the 1960's) to a figure as high as 100 per 10,000 (or 1:100). The increase in prevalence is largely due to changing definitions of Autism Spectrum Disorder, and improved knowledge and diagnostic services. There is no good evidence that the incidence has increased.

Management and Treatment.

Improved identification and understanding of Autism Spectrum Disorders has also meant improvements in management and treatment. Autism Spectrum Disorders are widely regarded as cognitive and developmental disorders, with specialised educational and behavioural approaches demonstrating the most consistent outcomes. Nevertheless, the use of medication to help manage the behaviours of people with an Autism Spectrum Disorder is high. This is especially the case for higher functioning individuals. A study in 1999 (Martin et al) showed that 55% of subjects were on medication at the time of the study and that 69% of subjects had received psychotropic medication at some stage.

There have been many claims of treatments that can 'cure' autism. An investigation by the New York Health Department in 2000 concluded that the quality of research into treatments for autism was generally poor. Many treatments have been proven neither effective nor ineffective. These include Holding therapy, Music therapy, Psychoanalysis, Physical therapy, Sensory stimulation/integration, Vitamins/diet, Son Rise/Options, Pet therapy and Irlen lenses. Some treatments that research has shown to be ineffective include Fenfluramine, Secretin, Facilitated Communication and Auditory Integration Training.

Reviews of the research investigating

(Continued on page 4)

(Continued from page 3)

educational and/or behavioural approaches such as TEACCH, ABA, Hanen ("More than Words"), PECS and Social Stories have concluded that early behavioural and educational interventions are a good option for children with autism - but there is no evidence in favour of any one approach, level of intensity, degree of structure or even age of commencement. These approaches seem to be most effective if they last at least six months, involve at least 15 hours per week (optimum probably 20 to 30 hours), have a high adult-child ratio, involve specially trained teachers and begin early (2 to 3 years of age), although there is no evidence that a delay in starting a program will mean less favourable outcomes.

Theory of Mind and Mind Reading.

Research has highlighted the inability of children with an Autism Spectrum Disorder to be able to Mind Read, or understand others' beliefs, feelings, thoughts or intended meaning. This results in deficits in social understanding and empathy; an inability to understand another's point of view and modify speech/behaviour according to context and impaired comprehension, reciprocal communication and abstract understanding or imagination.

There are several clinical implications of this inability to understand, including the impact of their own behaviours and/or speech on others, deciphering the underlying messages about the knowledge and understanding of others and responding to emotions.

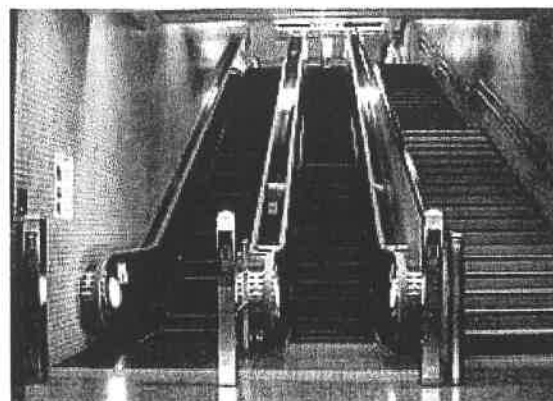
Teaching 'mind reading' skills has been shown to have positive effects on the person's belief and understanding skills, but the sample size is small. Further work is needed to establish if these positive effects are maintained, and to measure the impact on play and language skills and their awareness of individual differences? A key question is does the person improve their ability to mind read, or do they simply develop alternative strategies to solve mind reading tasks?

Functional Analysis.

Functional Analysis provides an effective approach for dealing with the challenging behaviours of children and adults with an

The story of the escalator.

Visiting the shopping mall was a favourite excursion for young Tom, especially the trip on the escalator. Why, then, did Tom become so traumatised by the escalator that shopping trips became impossible without a major tantrum?



The new sign on the left says, "Dogs must be carried". Tom interpreted this to mean he could only go on the escalator if he was carrying a dog!

Autism Spectrum Disorder. Functional Analysis assesses the reasons for problem behaviours. The focus of intervention should be on the underlying cause, not the surface behaviour. Do not focus on the tantrum, head banging etc, but on the factors that may be causing these behaviours, which is often because the person has no ability to control the environment by verbal means. Anxiety and distress occur because of a failure to understand what is happening, or why. It is important to remember that apparently inappropriate behaviours may be the person's only effective means of communication..

The first step is to assess the purpose of the problem behaviour - for example, to avoid or escape a situation, gain a desired item, or get attention. The next step is to teach the person equally effective ways to communicate his or her needs - by using pictures, objects, symbols or simple gestures or actions. It is also important to ensure that speech to the person is simple and concise (do the words really mean what you want them to mean?). You can augment speech by visual cues such as pictures, written lists and symbols.

Behaviours that may be acceptable in a young child become progressively unacceptable as they grow older. It is important to teach simple invariable rules from an early age. For example,

(Continued on page 5)

(Continued from page 4)

don't take off clothes in public, don't approach strangers, don't touch things in shops and don't talk about certain topics. Young children should also be taught basic social behaviours such as how to approach others; join in games with peers; basic hygiene and self-care.

Try to avoid giving attention for inappropriate behaviours, rather, encourage and attend to positive behaviours. When a child sits still and attends a task, tell them how good that behaviour is. The unexpected disruption of a routine or an unpredictable change will invariably result in distress, anxiety and aggressive like behaviour. It is important to prepare the person for disruptions and changes as early and clearly as possible.

Behaviours can be changed!

Obsessional interests, rituals and behaviours can limit the acquisition of other skills and interfere with other activities. The graded change approach can be used to minimise the person's reliance on these. The key is to *gradually* reduce the amount of time spent on the targeted activity and the number of places/people where it is allowed. Don't try and minimise too many rituals or behaviours at once.

Resistance to change and object attachments can be managed in the same way - gradually introduce planned change into the daily routine, help the person to predict change by use of pre determined schedules, visual warning cues and an explanation of what the change will mean. To reduce object attachment, gradually reduce the amount of time spent with the object, the number of places where the object is allowed, and if possible, the size of the object. For example, one child's attachment to a large blanket was reduced by gradually cutting the blanket down until it became small enough to fit into a pocket.

When dealing with ritualistic behaviours, treatment should aim to modify, not eliminate them. And remember that routines and special interests can be used as very effective rewards, are an important source of comfort for the child, can reduce anxiety and distress and may form the basis for social contacts as child gets older.

Other components of effective intervention involve focusing on changing the environment,

not the child, avoiding situations that trigger problems, improving others' awareness of the needs of someone with autism, ensuring consistency of approach and making the environment as predictable and controllable as possible. To increase generalisation, aim for close liaison between families and professionals, place emphasis on skills not weaknesses, minimise reliance on verbal cues, simplify social interactions and develop family, not child based interventions.

Autism into Adulthood.

There are very few studies of the outcomes for adults with an Autism Spectrum Disorder. A recent London study of 68 adults first seen as children showed that 22% had formal qualifications, 33% were working or in supported employment, 32% reported having some friends and 10% were living at least semi independently. These findings show that much work needs to be done to improve outcomes for adults. Lack of structure and predictability, boredom, low self esteem, isolation from peer groups and continuation of childhood behaviours that become unacceptable with age are some possible reasons for poor outcomes in adulthood. Interventions and support services need to focus on adolescents and adults, not just pre schoolers.

For a copy of the full transcript of Professor Howlins's presentations, please contact Autism Tas at autism@autismtas.org.au or the Secretary Cheryl Scott on cscott1@vtown.com. for an electronic version (PDF) or a hard copy.

Website

We apologise for any distress or inconvenience that certain images on the Message Board at the Autism Tasmania website may have caused. We hope that the Message Board will be up and running again soon.

CHANGING THE FUTURE FOR ADULTS WITH AUTISM

Professor Pat Howlin spoke on this topic to a group of 50 people at a seminar arranged by Autism Tasmania on Friday 12th March.

Prof. Howlin focused on five topics:

- 1 Outcomes in adulthood
- 2 Is there a difference between Asperger's Syndrome (AS) and High Functioning Autism (HFA)?
- 3 Is there evidence of deterioration in adulthood?
- 4 Psychiatric problems
- 5 Forensic problems
- 6 How can we improve outcomes?

1. Outcomes in Adulthood.

Prof. Howlin reported on a follow up study of 96 adults by Kanner in 1973. Eleven were functioning well and in jobs. Significant improvement had often occurred in mid/late teens as individuals became more aware of their problems, and endeavoured to improve themselves. Special interests were often important in finding work and in developing crucial contacts.

Comparing outcomes in studies published pre and post 1980:

She also reported on a study by Howlin, Goode, Hutton & Rutter in 2004, in which a group of 68 people with ASD were first seen at age 7 years and then again at age 29. All cases in this study had a non-verbal IQ of 50+ in childhood.

About 20% had gained formal qualifications, 32% had work or a supported income, 30% had some friends, and approx 10% lived semi/independently.

In terms of overall independence, 8% had good independence, 5% moderate, 24% poor, 48% very poor, and 15% in hospital care. There was also a general finding that childhood non-verbal IQ was an important predictor of later outcome, and that few individuals with IQ below 70 as children were living independently as adults. However there was little difference between individuals with initial IQ of 70+ and those of 100+. Factors other than IQ were important.

2. Outcomes in individuals diagnosed with High Functioning Autism (HFA) or Asperger's Syndrome (AS).

Prof Howlin noted that Lorna Wing had, in 1981, "resurrected" Asperger's original account as a useful shorthand term for individuals with autism of high IQ/good language. In 2000, Wing argues against its existence as a separate entity, as the distinction has led to problems in research, clinical work and for support/funding.

Prof Howlin then presented some information comparing individuals with autism and AS. There was no differences in most variables though the nature of ritualistic stereotyped behaviours may differ.

	Good/fair outcome	In Work	In own home	In hospital
% pre 1980	34	8	2	54
% post 1980	60	24	12	10

This indicates that there is a general improvement in outcome post 1980.

In summary, studies have been small scale and apparent differences seem to disappear when groups are appropriately matched for IQ, and an increasing number of studies suggest that any differences may decrease with age. Although the AS individuals may not have marked language delays in early childhood, communication in adulthood is often markedly impaired.

The fact that some studies indicate more problems in HFA groups, is likely due to their more severe language impairments as children, and the impact of these on developmental trajectory.

3. Do people with autism deteriorate in adulthood?

Prof Howlin reported that some subjects showed an increase in hyperactivity, aggression, destructiveness, rituals, inertia, loss of language and "slow intellectual decline", but that this was most marked in individuals with lower verbal IQ, with epilepsy and those in long-stay hospitals.

(Continued on page 7)

(Continued from page 6)

Kanner's own follow up (1973) of 96 adults found that significant improvement often occurred in mid/late teens; and there is evidence from an increasing number of studies that certain behaviours increase with time. There are increases in verbal IQ, improvements in self awareness and self control.

4. Is there evidence of greater psychiatric disturbance in adulthood?

The general conclusion is that the rate is 0.6%, which is no higher than in the general population. Often though, adult psychiatrists know little about developmental disorders and symptoms are misinterpreted due to inappropriate verbal or emotional responses, or unusual ways of describing symptoms. This may lead to incorrect conclusions and treatment.

5. What are the risks of forensic problems?

There are only a handful of cases described in the literature, and this represents a *tiny* proportion of all autistic cases described. Individuals are probably less likely to offend than other groups because of their rigid sense of morality. If problems do occur they can be difficult to resolve because of lack of awareness by the culprit of social impact, implications for self, or potential for harm.

Factors leading to psychiatric or forensic problems in adults are often related to obsessional interests or preoccupations. There is a need to ensure that behaviours that are acceptable in a small child do not persist into adulthood. Problems may be due to a desire for friendship and may be due to a mistaken interpretation of cues.

6. How can the situation be improved?

- Improve education – increase understanding by teachers and improve curriculum and aids for teaching.
- Address factors leading to psychiatric and forensic problems.
- Establish rules from early on - remember what is clever, cute and charming at 3, can be a disaster at 30!
- Sexual problems – These are often social problems. From an early age teach basic rules, including how to say NO to others' demands. Foster realistic expectations in early life, and increase wider social contacts as much as possible.

- Make use of existing skills to encourage social contacts, increase social status, and enhance self esteem.
- Create an autism friendly environment – visual cues, appreciate the disparity between verbal and written comprehension, understand the importance of routines, need for consistency and predictability, and the need to have control over the environment.
- Improve opportunities for social inclusion.
- Prof Howlin also spoke about a London based scheme for employment.

• Conclusions

Essential needs are:

- Early diagnosis.
- Management advice for parents.
- Modification of special skills to promote social interaction.
- Appropriate education.
- Recognition by social health and employment services of needs of adults with autism.
- Variety of options for supported and semi/independent living.
- Help for more able individuals to understand and cope with the enigma that is autism.

Professor Howlin was an engaging speaker, whose common sense and logical conclusions were well received by the audience.

Penny Cromarty.

For a copy of the full transcript of Prof Howlin's presentation, please contact Cheryl Scott at Autism Tas for an electronic version (PDF) or a hard copy

autism@autismtas.org.au

Congratulations!
Congratulations to Mick Clark who has recently been elected President of the Autism Council of Australia.

Making Smarter Use of Medicines for Autism

by Peter Hill, Pharmacy Manager Jerudong Park Medical Centre

Below are extracts from a presentation from the first National Autism Conference of Brunei 2003

Finding reliable information

Searching for autism and drug medication on the Internet returned 93,000 hits in April 2002. In March 2003 the same search returned 204,000 hits

Be careful of those who promote cures especially newspapers and television.

Remember medications do sometimes have a role to play in the control of symptoms, but there is no drug that will cure the core social and communication problems.

The variety of disorders is so wide that success for one person doesn't mean others will find the same benefits.

Medication Tips

- Be as well informed as possible about the medicines being prescribed. Never be afraid to ask questions.
- Keep records and notes of tests, blood results, prescriptions, doses, assessments and follow ups.
- Keep a diary of your child's symptoms, behaviour and side-effects.
- Don't start or stop prescription medications on your own.
- Always tell your doctor or pharmacists all of the medicines your child is taking. Even 'over the counter' medicines and supplements can interact with prescription medications.
- Expect to begin with low doses with slow increases (every 2 weeks or so) if symptoms don't improve.
- You may need to reduce the dose if side effects occur.
- Be accurate when cutting drugs into halves or quarters - use a tablet cutter.
- Use a proper measure for liquid medicines. Don't use teaspoons - they vary from 3 - 8 mls in size
- Check with your pharmacist before crushing tablets.
- Always check the expiry date of the medicines you are giving.

- Never share your medicines with others.

Be wise with medicines

- The effects of drugs vary greatly from one child to another. We cannot generalise about the supposed benefits of medicines.
- Medicines are not a substitute for proper education, training and intervention.
- Because autism is the result of many different causes, it is impossible to predict whether a drug will benefit an individual, and no drug has been shown to benefit all people with autism.
- The use of powerful drugs is best avoided in children unless there are distinct benefits.
- To evaluate a medicine properly, do not change other therapies at the same time.
- If a person has been on a medicine for a long time it must never be stopped suddenly.
- Allow sufficient time for the new drug to work. Some medicines take 2-3 months to show full benefit.

How to tell if a drug is working

If possible, don't tell anyone about the new treatment, this is called a blind evaluation. *If change really occurs then it likely that teachers, friends or relatives will comment. You might even like to try a blind evaluation yourselves by arranging that neither you, your doctor, or child know whether you're giving an active drug or an inactive 'placebo'.*

Ask people to write lists of what changes they have noticed - compare this to your own diary.

Adverse Effects

There is no such thing as a drug without side effects, especially those that are acting on something as complex as the brain. Expect side effects to occur.

It is important to be watchful of side effects, especially since the children and adults with autism who are taking them are often able to report unwanted effects.

Remember that higher doses always mean better results. A higher dose can have the opposite effects of a low dose, and worsen the condition.

Where it all Begins

Self awareness, behaviour and personality are a

(Continued on page 9)

(Continued from page 8)

function of the brain as an integrated system.

Our perceptions of the world around us depend on millions of interactions among nerve cells within the central nervous system.

A neuron may process information from 100,000 different sources, and there are more than 20 billion neurons in the nervous system.

We seldom realise how complex these processes are unless they go wrong in some way.

Communication

The brain cells 'talk' to each other by the uses of chemicals (transmitters).

There are about 50 known transmitters.

Many symptoms of behaviour and emotion are due to the transmitters being unbalanced.

Coordination

At any moment, millions of sensory neurons are delivering information to processing centres in the brain and millions of other neurons are controlling or adjusting the activities of our bodies. This process continues 24 hours a day, whether awake or asleep.

Millions more neurons are involved in our thoughts, consciousness, behaviour, emotions, sociability, expressions, personality, and interactions with others.

Principles of Drug Therapy

In autism there may be problems with either the integration and connections in key brain areas, or the chemical systems that allow nerve cells to 'talk'. It is difficult to predict the effects of medicines in the brain, and predicting effects in the brain of a person with autism is even more difficult.. Thus, the effects of medicines in people with autism may be different to the rest of the population and may differ widely between individuals with autism.

There is good evidence that as well as a possible problem with the chemical messengers in the brain, there is an abnormal pattern of cells in some areas. This can not be treated with medications.

When we are better able to understand the genetics, the anatomy and biochemistry of the brain in people with autism we may be able to develop better drugs. Until then it is often a trial and error process, especially in those with severe to multiple symptoms.

What's new in drug therapy for Autism?

There is more research than ever with many clinical trials happening worldwide.

There have been huge advances in understanding the genetics of autism.

February 2003, the location of the gene for insistence on sameness discovered on chromosome 15.

Children with autism who show this condition have repetitive compulsions and an extreme resistance to even minor changes.

This faulty gene is located in the same area as those known to be responsible Angelman and Prader-Willi syndromes.

Chromosomes 2 and 7 also appear to be involved. Chromosome 2 has also been linked to speech delay.

There is continuing interest in the 'gut brain' axis although the significance of it unclear.

There is increasing anxiety about the increasing incidence of autism.

Rates in California jumped by 22% in 2002 - not all of this can be explained by better diagnosis.

What does this mean?

Perhaps people with inherited gene defects linked to autism are more likely to suffer unusual reactions to triggers.

Perhaps the genetic problems make people more susceptible to autism, but it only happens when certain environmental factors kick in.

Perhaps this explains the higher incidence of disorders such as allergies, asthma, eczema and epilepsy.

Individual medicines

Prozac (fluoxetine) (oral capsules).

Appears to be beneficial in the control of obsessive compulsive rituals. Can also be useful in anxiety and to improve socialising, communication and the ability to deal with change. Can cause problems with restlessness, anxiety, insomnia, decreased appetite and agitation. Can take up to a 2 months for full benefit to show.

Risperidal (Risperidone) (oral tablet)

Reported improvements in social interactions, attentions and awareness. Decreases in impulsive aggression, agitation, anxiety, hyperactivity, repetitive behaviours, self injury.

(Continued on page 10)

(Continued from page 9)

Side effects include sedation, weight gain (the weight gain can be very significant (up to 5kg in several months in recent trial).

Valproate

This antiepileptic is used to stabilise moods and control problem (especially violent) behaviour. Because many children with autism suffer from seizures it can be particularly useful. It can cause sedation and (rarely) liver damage.

Ritalin (Methylphenidate) (oral tablet)

Used to control hyperactivity and inattentiveness. The drug probably works better in children with Asperger Syndrome or with higher – functioning children UP to 10% of those with Asperger can be classified as having hyperactivity disorder. Positive results include a decrease in impulsiveness and aggression.

Anafranil (Clomipramine) (oral tablet)

Related to Prozac in the way it works. May reduce repetitive behaviour, rituals, aggression. May improve ability to socialise. Children can be less withdrawn, angry and anxious. Side effects include insomnia, constipation, sedation, dry mouth and urinary retention. Two reports of increased aggression. Major concern about seizures and ECG changes.

Tegretol (Carbamazepine) (oral tablets)

Used to control epilepsy and to smooth out mood swings including aggressive behaviour (can also use Epilim). Mood swings also treated with Lithium.

Vitamin B6 (pyroxidine) (oral tablet)

Usually taken with magnesium to reduce side effects and improve activity. Supporters claim that 35 – 40% of people with autism will show improvements in areas as attention, learning, speech, eye contact

Melatonin (oral tablet)

More than half of children with autism show some sleep problems. Melatonin is produced naturally in the brain to create normal sleep rhythms. It is possible that children with autism don't secrete enough of this substance leading to difficulties falling and staying asleep. It is given once a day, about 30 mins before normal sleep time.

Secretin (injection)

This is a hormone found in the intestinal tract and the brain. There were reports from many parents who claimed to observe improvements in

their children after secretin injections. Recent well constructed trials have disputed this, with very few children showing a long lasting response.

The MMR Controversy

Wakefield (1988) suggested a link between MMR vaccination and the onset of autism in 12 patients. A huge amount of research has been undertaken since then. The consensus of opinion is that there is no evidence to support the theory based in the available data. A Danish trial (2002) monitored nearly 540,000 children. 82% had been vaccinated. No difference between vaccinated group and unvaccinated group.

Summary

Drug therapy is directed around the disordered behaviours and symptoms. There is no drug therapy that can cure the underlying problem.

The drugs are often powerful, and side – effects are common.

It is vital to take medicines as prescribed. Many failures in drug therapy happen because instructions aren't followed.

Your rights with medicines

Finally,

It is your fundamental right as a parent and consumer to be given all the information you need to manage your child's medicines properly.

Never be afraid to ask questions about medicines.

Demand answers if you are not satisfied with the information you receive, and seek out those health professionals who treat you and your child with dignity and respect.

Medications should be viewed as a method that prepares the brain's chemistry in such a way that learning can be optimised. It is neither a cure for autism, neither is it a competitor to or a replacement for other models of treatment

Peter Hill – Reprinted with permission.

Breakthrough in Understanding the Development of the Autistic Brain by Dr Jacqueline Roberts *reprinted from Autism NSW Keynotes, Summer 2003/4*

Dr Jacqueline Roberts. is a consultant specialising in Autism Spectrum Disorders.

At the Autism World Congress in November last year, Dr Eric Courchesne of the University of California, presented the findings of his group's research into brain development in autism. These findings have been published this year in the Journal of the American Medical Association and are presented in this article along with related research from Dr Courchesne's group. The search for the underlying causes of the many and varied behavioural symptoms and developmental outcomes of autism is ongoing as researchers attempt to explain the triad of impairments across the autism spectrum. It is not unexpected that multiple sites of anatomical deficits of the central nervous system have been hypothesised to underlie different symptoms of autism. While it is unlikely that a single cause will be found to explain all the variations of the autism spectrum, there is a growing body of biological research into brain development in autism which is showing consistent and significant results (in research papers 'significant' is a precise term which means that the possibility of something occurring by chance is less than .01% or .001%).

In this article we look at three important research studies into the development of particular parts of the brain in children with autism, which show consistent and interesting evidence of some aspects of brain development that may explain many of the behavioural characteristics of autism. These studies look at the overall growth of the brain in infancy (Courchesne, Carper and Akshoomoff, 2003) and at development in the frontal cerebrum and the cerebellum (Carper & Courchesne, 2000); and development in the limbic system, (Saitoh, Karns & Courchesne, 2001). Carper and Courchesne (2000) examined the frontal lobes and the cerebellums of 42 children with autism, 3-9 years of age, and 29 matched typically developing children using Magnetic Resonance Imaging (MRI). They found that anatomical abnormalities of the frontal lobe occurred in many of the children with autism, a finding that

is consistent with post mortem studies. Structural abnormalities in the frontal lobe would be expected to affect attention, working memory and problem solving. They also found a very high rate of cerebellar abnormality in children with autism, particularly a variable degree of Purkinje cell reduction or abnormality. These cells are rich in the neurotransmitter, serotonin. The cerebellum coordinates movement of muscles and joints by synthesising data from the brain stem, the spinal cord and the cerebral cortex (which includes the frontal lobes). Carper & Courchesne (2000) found that the degree of frontal lobe abnormality found in children with autism was correlated with the degree of cerebellar abnormality. That is, the higher the level of frontal lobe abnormality, the higher the cerebellar abnormality. This correlation suggests there is a developmental link between the two brain structures. We do know that there is an analogous relationship in that the frontal cortex and the cerebellum perform possibly complementary functions. For example, the cerebellar cortex is activated by tasks which commonly activate the frontal cortex; working memory, attention and semantic association. The abnormalities in both could be caused by a common event such as gene mutation or very early (before or just after birth) exposure to environmental toxins (these events could also affect other brain regions), or alternatively, anatomical abnormalities in one area could cause maldevelopment in the other via neural pathways. If this is the case abnormal neural activity caused by the reduction in Purkinje cells in the cerebellum could cause maldevelopment of the frontal lobe. During the course of development the neural connections between these two misconstructured regions of the brain would continue to have a detrimental effect on development. Because the two regions are domain compatible, (ie. they share similar functions), if both are damaged the potential for functional compensation as is seen in cases of brain damage involving one or the other area is greatly decreased.

The limbic system is a part of the brain thought

(Continued on page 12)

(Continued from page 11)

to have a primary role in the regulation of emotions. It is made up of three structures: the olfactory cortex, which is the centre for smell; the amygdala, which is the centre for fear and flight/fight; and the hippocampus, which is primarily involved in memory. Developmental defects in the limbic system were hypothesised as likely causes of autistic symptoms because this system mediates, memory, social and affective functions. Saitoh, Karns and Courchesne (2001) studied the limbic system of 59 participants with Autistic Disorder from the age of 29 months to 42 years, and 51 controls using MRI. They found that the cross sectional area of the area dentate (AD) which is part of the hippocampus, was significantly smaller than normal in autism suggesting undergrowth in this area. They found that abnormality in the AD existed in the youngest participants through to the oldest in comparison to the typical controls. In typically developing children the limbic system is a part of the brain that is amongst the last to develop a full complement of neurones.

The authors suggest that in autism the maturing of this part of the brain is even further delayed resulting in a delay or disorder in the emergence of typical hippocampal memory function in autism. The authors also suggest that recent evidence shows that cells in this area continue to form throughout life and that the rate of neurogenesis (new cell formation), in primate brains at least, increases in an enriched learning environment and decreases in conditions of social stress. It appears from this research that in autism, limbic abnormalities affect memory and learning in particular.

Brain over growth at critical developmental stages has been suggested to be associated with autism. The size of the brain is directly related to head circumference, therefore the bigger a child's head the larger their brain. Courchesne, Carper and Akshoomoff (2003) evaluated the head size or circumference of 48 children with autism, some were diagnosed as Autistic Disorder, some as PDD-NOS (Pervasive Developmental Disorder not otherwise specified, which includes Asperger's Syndrome and atypical autism). These children were part of a cohort of research participants who had had MRI as part of a large study into the brain development of children with autism. The children with Autistic

Disorder and PDD-NOS in this study were 2-5 years of age at the time of their MRI. Head circumference is routinely measured and checked for all children at regular intervals from birth.

The authors looked back at medical records for each child's head circumference (HC) measurements and found that HC at birth in the autism group compared to population norms, was significantly smaller, while body length and weight were the same. In the autism group between 1-2 months and 3-5 months and again between 3-5 months and 6-14 months HC increased significantly in relation to the population norms. As a result between birth and 6-14 months of age the mean HAG of infants with autism increased from the 25th percentile (which means that 75% of the typical population had bigger heads) to the 84th percentile (which means that only 16% of the typical population had bigger heads). Body weight and length continued to be the same as the population norms. The possibility of this increase in HAG relative to the typical population occurring by chance is less than .001 of a percent. When the authors compared the HAG of the two groups of participants, those with Autistic Disorder and those with PDD-NOS, there was no difference between the groups at birth, both groups had on average small heads compared to population norms, but the same length and body weight. However there was a striking difference between the groups over time in that the Autistic Disorder group HAG increased relative to the population norms at a significantly greater rate (reaching the 95th percentile between 6-14 months) than the PDD-NOS group which increased at a slower rate reaching the 54th percentile. Differences between the AD and PDD-NOS groups suggests that an earlier onset, faster rate and longer period of excessive brain growth might be associated with a poorer outcome. The authors also found that the MRI at 2-5 years showed that small HAG at birth was correlated significantly with smaller cerebellar grey matter volumes at 2-5 years, while greater increase in HAG during the first year was significantly correlated with increased cerebral (including frontal lobes) grey matter.

(Continued on page 13)

(Continued from page 12)

In summary the authors found a rapid and excessive increase in HAG and by association in brain size beginning several months after birth. The increase occurred well before the typical onset of behavioural symptoms of autism and correlated strongly with greater cerebral and cerebellar volumes as measured with MRI at 2-5 years of age. The authors suggest that this "growth dysregulation" of these two major cortices and underlying white and grey matter in the brain underlies the increase in HAG. The exact nature of the cellular bases for this growth and the causes have yet to be identified. Although an abnormally large increase in HAG in an infant cannot be viewed as a certain and unique marker for autism it does appear to be an important signal that an infant is at a significantly heightened risk for the disorder. Most importantly brain overgrowth occurs at the beginning of an important period of developmental neuroplasticity and learning. In autism the brain may compress into a short time an amount of overall growth that takes many years in typically developing children. Faced with the neural noise that would be the result of such rapidly changing aberrant connections, it is highly likely that the infant would lose the ability to make sense of his world and withdraw. In conclusion the evidence of characteristic differences in brain development in autism outlined above is consistent with the more general hypothesis that

autism involves widely distributed aberrant functional organisation in cerebellar, cerebral (especially frontal lobe) and limbic regions. These defects appear to underlie multiple cognitive and behavioural deficits. Clearly more research needs to be done to further clarify this complex issue, however it is suggested that this evidence does in part indicate that vaccines, childhood exposure to environmental toxins or pathogens, or unusual gastrointestinal or allergic reactions to food are not logically plausible as causes of brain overgrowth in infants. However some may argue that such later occurring events might be important as aggravating factors. This leaves the key question, what triggers the abnormal brain overgrowth initially in the first months of life?

References:

- Carper, A., & Courchesne, E., (2000). Inverse correlation between frontal lobe and cerebellum sizes in children with autism. *Brain*, 123, 836-844.
- Courchesne, E., Carper, R., & Akshoomoff, N. (2003) Evidence of brain overgrowth in the first year of life in autism. *Journal of the American Medical Association* 290, 3.
- Saitoh, O., Karns, C. M., & Courchesne, E. (2001). Development of the hippocampal formation from 2 to 42 years. MRI evidence of smaller area dentata in autism. *Brain*, 124, 1317-1324.

About Carers reprinted from Autism News (WA) Sept 2003

Being a parent or carer is not easy. It requires large doses of patience, energy and hard work. In this article, we examine some of the hazards of caring and ways we can deal with them.

Stress and Exhaustion

Being a carer is a 24 hour a day responsibility. Of course, different people require different amounts of care. However, whether the individual is relatively independent or requires constant assistance and supervision, caring for their needs places extra demands on the carer. For most carers, these demands are in addition to the other demands of everyday life; earning a living, keeping house, taking care of other family

members etc.

Health impacts

Both stress and exhaustion lower the efficiency of the immune system, making us more vulnerable to all kinds of illnesses. Interrupted sleep can also have quite a serious effect on the immune and endocrine systems. In addition, stress and exhaustion may mean that carers neglect to do the things that maintain good health.

Guilt, Resentment, Anger and Frustration

Can be natural reactions to the stresses and demands of being a carer. These emotions can

(Continued on page 14)

(Continued from page 13)

be destructive, however, when carers get 'stuck' in those feelings and are unable to regain their normal equilibrium, they can also be destructive when they have negative effects on other members of the family or on carers' relationships. Sometimes the most difficult thing about these emotions is that we feel guilty for having them, making the situation even more difficult to cope with and the feeling of isolation even greater.

Isolation and Boredom

Ironically, carers can be busy, exhausted and bored all at the same time. Sometimes care giving can entail spending a lot of time doing tasks that, while they may occupy a lot of time and may be quite tiring, are also quite tedious. It can be difficult for carers to find the time and energy to remain involved in things that really interest them and large chunks of their time may be quite uninteresting.

In addition, caring can be isolating in a number of ways. Often the amount of time spent in providing care means that there is very limited time available for socialising. Others may not understand the situation and may react negatively, or the characteristics of the individual being cared for may make it difficult to mix. (For example, it is unlikely that taking a very sound-sensitive person to the Royal Show will be very successful.)

What can we do?

Accept our shortcomings. Or as it was put to me "you're not perfect - get over it". There will be days when you are not as patient as you should be. There will be days when you just don't want to do this any more. This does not make you an evil person or a bad carer. It makes you human. This is a normal, natural response to a very difficult situation.

Talk with others

Talking to family and friends and especially to others who share the experience can make a huge difference. Simply letting off steam' can really help. In addition, of course, talking can help solve problems, garner support and just provide that human contact that we need to buffer us from isolation. It also helps to provide some of the fun and interest to life that we all need and that can be endangered by the demands of the caring role. Letting others know where you are coming from can also help them to be more supportive and understanding. Remember, a lot of what we do may not be obvious to others. Even

when they see examples of what we do all the time, they do not understand what it is like to do what we do all the time unless they have experienced it for themselves. They cannot understand unless we help them to do so.

Seek out help

Remember, caring is a job that is 24 hours a day, 7 days a week. No 'real job' makes such demands. We know that people simply couldn't work effectively as a teacher or doctor or truck driver if we asked them to be on duty all the time. Carers are on duty all the time and the demands made of them can be huge. Therefore to enable them to remain effective, and to avoid damage to their welfare, and the welfare of those around them it is imperative that they receive assistance.

"Sometimes the most difficult thing about these human emotions is that we feel guilty for having them, making the situation even more difficult to cope with."

Be aware of the big picture

I call it "The I can cope syndrome". Frequently we do not get the help we need because we focus on the detail. As each specific issue comes up, we say "I can cope with this." And we can. The problem occurs when we keep doing this ad infinitum. This approach doesn't allow for the fact that this is one in a long series of issues. The criterion is not "can I cope with this particular issue right now?" because the answer is almost always yes. We can always cope with one more thing until we are totally depleted. We need to be aware of the big picture so that we don't suddenly get to the point where we are totally depleted and can't cope.

"Just say no"

We are often tempted to say "yes" to things because we feel that other people are expected to do them and we can't use the "excuse" of being a carer to "get out of" these normal tasks. We can! The school will survive if you say no" to being canteen lady. Your friends will still enjoy dinner at your house if it turns out to be pizza. If being canteen lady or cooking dinner is going to add significantly to your stress level, don't do it.

Take care of our own physical, mental and emotional health. Often we see this advice in articles like this and we think it is good advice, but not advice that we can take. Taking time to exercise or cook healthy meals seems an impossibility if we are struggling to get through

(Continued on page 15)

(Continued from page 14)

each day. Despite this, it is important that we make taking care of our health a priority, not only for our sake, but for the sake of those who depend on us.

Take a break

Often carers who have been desperate for a break find that when it actually arrives, they are reluctant to hand over to someone else. After all, we know the person best. We can interpret their communication when no-one else can etc etc. Often we feel quite lost when we first get respite. We don't know what to do with ourselves. We actually have to teach ourselves to take a break. At first it may be difficult. In fact, it can be more demanding than taking care of the person, we think. However, it is absolutely necessary in order

to ensure that we are going to have the capacity to go on caring for that individual we care about and love.

It's a Marathon, not a Sprint

So pace yourself, give yourself time. If you have a partner make a conscious plan that each of you will support the other when one is feeling low, tired or angry. Take time to care for each other, as well as your son or daughter with Autism.

Reprinted with permission of the Autism Association of Western Australia

AUTISM and AAC

This item comes to us thanks to Tracey Bode, a Victorian Speech Pathologist who works for ZYGO – Australia, a company which produces communication devices for people who have disabilities. She commented that this Question and Response, which she read on a message board in the US, provided her with a valuable insight into the workings of the mind of a person with an ASD. It is reproduced here for your interest

Question

I have a question about this issue. I know very little about Autism, no matter how much I learn about it, but it is my understanding that people with autism have difficulty connecting with people (I don't know if I'm stating this correctly). If this is the case, why would an AAC (Assistive and Augmentative Communication) device improve communication enough to warrant it? Are there any good efficacy studies someone can point me to? I can understand if there are speech-language issues in addition to the diagnosis of autism, but please help me understand this issue further.

Response

I am autistic, so I have some first-hand knowledge of this. I can communicate in text and with AAC devices in a way which I cannot with speech. I can talk, and often do. But often, I find my speech is very echolalic - I'm repeating back phrases or sentences from someplace I've heard in the past, without ever having any conscious thought about them.

For me, expressive spoken language - especially

expressing my personal needs or emotions - is very difficult. Speech is my "second language" (I in fact have a significantly different set of vocabulary for speech than I do in writing and I have to learn a spoken word separately from its written equivalent). While I don't currently have any problems with the mechanics of speech, I do have significant problems with the cognitive issues surrounding speech. I think it is probably also related to hearing my words as I speak them - it is very distracting and causes me to lose track of "where I am", even mid-sentence.

I remember the first time I used a speech synthesiser to talk to a dentist, for instance. It was the first time I had ever been able to actually say, "I think my bite is messed up on the right side." That's a significant thing for a dentist to know, but something which I would have been unable to say with speech (and had been unable to say for about 5 years). I was so happy that, later in the day, as I thought about actually being able to communicate, I ended up running around in circles (something I do when I am really happy). It's also let me say things to my friends, like, "I really enjoy our friendship." These are really important communications.

*Other autistic people who use AAC either full or part time tell me that they can't get their mouths to make understandable sounds - that what they hear isn't what everyone else hears. Others say it is similar to my reasons. Others find it impossible to speak *and* think about what to say at the same time. Joel*



**THE JOURNAL OF
AUTISM TASMANIA
INC.**

Postal Address
PO Box 1552
Launceston
Tasmania 7250

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

www.autismtas.org.au

Contact the
**Autism Tasmania
Family Support
Coordinator,
Rose Clark**

on
6423 1086 or
0407 320 048
or
autism@autismtas.org.au

The Family Support Coordinator Role explained:

In June 2003, Autism Tasmania appointed Rose Clark as Family Support Coordinator. The role of the Family Support Coordinator is an evolving one, as it develops to meet the needs of members. So what is Rose's role and who has access to her?

The family Support Coordinator provides an initial point of contact for members seeking information about Autism Spectrum Disorder throughout the state. Rose is currently working from home, available by phone or e-mail. However, the developing Family Support Service is directly supported by Giant Steps where a room has been provided at no cost. Eventually this room will become the administrative centre for Autism Tasmania, being a base for the FSC, the library and administrative functions of the organisation.

Overall, Autism Tasmania's new Family Support Service has four primary aims for helping people at the various stages:

- To build a service that directly helps individuals and families of people with autism, by providing information and explanation, emotional support and counselling.
- To provide balanced and appropriate advice about specific situations, difficulties, resources and service options
- To provide advocacy on families behalf with other agencies.
- To develop a volunteer peer support network throughout

Tasmania that increases the capacity of individuals, parents and families to support each other.

Rose travels the state widely and readily, having established support groups in Hobart, Launceston, on the North West Coast, the East Coast and also visits the West Coast. These groups have fairly clear ideas about the type of activities and information required and Rose organises guest speakers to attend. Support group activities are published in the bulletin and reminders are also sent out via e-mail.

The Family Support coordinator is currently employed for two days per week, and we are fortunate that Rose is flexible with how this time is allocated. However demand is far outstripping the time available and priority is therefore given to members. Rose was initially appointed for 100 days and this has been extended until the 31st December. Continuation of this position will depend upon successfully securing funding from a variety of sources.

Ros Ward (President)

Did you get yours?

The last Autism Tas Bulletin was sent out during the first week of May via e-mail to members who supplied us with an e-mail address and via snail mail to all others.

If you did not receive a copy, either electronically or as a hard copy or if you would prefer to receive your bulletin in a different format, please let us know.