UPDATE

A4 Autism Aspergers Advocacy Australia

April 2004
Issue 2

Feature

By Tim Bull

Like many parents I suppose, the first hints from the paediatrician that our son might have autism sent us diving for dictionaries and encyclopaedias.

We had heard of it, but had little understanding of it. "Morbid absorption in fantasy, condition preventing proper response to environment," they read.

Of course these are very general descriptions and the authors of the Oxford could obviously not afford the 100 plus pages it would take to properly explain the complexities of this affliction.

However, the more we read and studied about autism as we watched our son develop, the more we realised many of the items, articles and experiences we had read were about children that had very little in common with our son.

It soon became apparent to us that autism was a very complicated complaint that was basically unique in each child that received the label. Yes, they often have many similar characteristics, strengths and weaknesses, but in many ways they are also so very different.

Living in the country town of Bairnsdale we immediately considered moving to receive the best therapy we could. To say we were horrified to find waiting lists at places like Irabina and the Mansfield Travelling Teacher Service is an understatement and remains a situation we continue to lobby strongly on.

However, one important piece of advice we received was to stay close to family as their support would play a crucial role in our son's development - never a truer word was spoken. The respite we receive allows us to keep the batteries charged (most of the time) and the hours he spends interacting with his young cousins is I'm sure, the best therapy he receives.

We immediately put our name down on waiting lists and in time received a placement at Irabina Early Intervention Centre at Bayswater one day per term. While this doesn't sound like much, it proved invaluable.

Our son Daniel obviously received limited time, but we both attended with him and were able to bring back a lot of the initiatives and therapies learned at Irabina and incorporate them into our own home program. The three monthly visits also allowed the specialist staff at Irabina to monitor Daniel's development and give us ideas to work on for his next stage of development.

These visits were also supported by phone advice and I have no doubt even this limited access to Irabina had a hugely positive impact on our son Daniel's development.

Soon after we began to receive service from the Mansfield Travelling Teacher after what I believe was a disgraceful 16 months on the waiting list – no fault of Mansfield's, just a lack of governmental support. Like Irabina, Mansfield has proved a wealth of knowledge and a very worthwhile service — one we still receive.

Through these efforts our son is now attending mainstream school, an achievement we, at one stage, never thought possible. We are unsure of how long he will be there and if the demands of the higher grades will become too great, but he is continually surprising us with his development.

We are under no allusions the future will be difficult, but Daniel has come a long way and has already developed to a level we never thought he would.

He did not talk until he was four and a half, but is now engaging in conversation, commenting on things around him and playing with other children.

If there is one piece of advice I can give to parents of recently diagnosed children, it would be to get you names on waiting lists immediately, even if you are unsure about the service, because there is plenty of waiting time to make up your mind.

Also, trust your instincts as a parent, you know your child best. There are many wonderful specialists out there who can help so much, especially in the initial stages, but you are your child's best therapist and best teacher.

Good luck to you all.

Inside This Issue

Note

The A4 Update will now be emailed to all members of A4 on a bi-monthly basis beginning this April. Therefore the next edition will be out at the end of June. All reader's contributions and inclusions for the June issue must be sent to edit@a4.org.au by June 9 for the next Update. All contributions are encouraged and welcome.

From the Convenor

By Bob Buckley

Dear A4 member

Since Beechworth, I have spent two days representing A4 at a local autism conference in Townsville. I met some great people. Hopefully the people I spoke with will be able to get better outcomes for people with autism in their region.

As a result of an event at Beechworth, I met with the FaCS backbench committee in Canberra. That lead to a meeting with FaCS. I'll say more about that in my next message.

Perhaps you have noticed, autism is attracting more media attention at the national level. An article appeared in the Bulletin on March 31 and there were a number of letters to the editor the following week.

The Australian had an article by Leigh Dayton and Helen Tobler headed *In the eye of the beholder* on April 17. A4 cannot claim to have initiated any of this publicity though we have contributed. We hear from the media that each story about autism attracts a high level of feedback. Interest is building, so please ... whenever you can find something to say. Say what you feel but your message will be more effective if it includes something positive.

A lot was discussed at Beechworth. I am really sorry that I have not been able to get the information ready to send out in this Update. My next message will contain the notes from Beechworth and I will be asking for your input. The job of Convenor has been more than I could manage this last couple of months, on top of being a part of my family, doing my paid employment and activities at state-level. Be warned ... we need help and I will ask for it. There is so much to do and currently we do not have enough volunteers to do it all.

I regret that A4 has not got a great plan for the coming Autism Awareness Week. Instead, please get involved in your state's activities. We hope to develop the best local and state ideas into a national activity next year; we already have our eyes on some of those. If you are not sure what is happening in your region, please contact you favourite state or local ASD group and help them with what they are doing.

I sent the letter below, on behalf of A4 members, to the federal minister for health and his parliamentary secretary. If you agree with what the letter says and wish to increase autism awareness in your state government, please send a copy of A4's letter to your own state health minister with a few words of your own suggesting services for people with autism need to improve. Or feel free to copy as much of the letter as you like to make up your own letter ... plagiarism is currently the rage in Aussie politics, and imitation is the sincerest form of flattery.

A4 will be holding an event in Canberra to coincide with the Biennial Autism Conference. The form of the event is taking shape. The conference website is http://autismact.homemail.com.au

Letter to government

The Hon. Trish Worth MP
Parliamentary Secretary to the Minister for Health and Ageing
Parliament House
Canberra ACT 2600

Dear Ms Worth MP

I received your letter dated 19 April 2004 in response to my letters dated 6 and 30 October 2003 on behalf of the Minister, Tony Abbot MP. I note your regret over your delay in responding. I am particularly sorry that the opportunity to influence the direction of government spending in the coming budget and leading up to the election has been missed.

Thank you for pointing out responses to Senate Question 1992, Hansard, pages 17207-09 and Question 2186, pages 17766-67. Senate Question 2397 and House of Representatives Questions 2559, 2657, and 2663 also address the subject of autism.

You are correct: I had a short discussion with Mr Dermot Casey of the Health Department, but I have heard nothing since. Your response and those the Minister gave in Parliament show that there has been no outcome from that discussion. Nor is there any discernible intention of further government action.

Where is the government getting its advice on autism? My discussion with members of the Health Department established that the department is not in a position to advise the government on the subject of autism. None of its staff have a sufficient level of knowledge or experience of the topic. Having discussed autism with the relevant members of the AIHW, the same conclusion applies to that organisation. There is nowhere for the government to go for comprehensive advice on autism. This government is not doing anything to address this lack of crucial information. It appears this government does not want to be told about autism. Nor is the opposition planning to do anything.

Your letter observes: "early diagnosis and appropriate educational programs are very important to children with Autism Spectrum Disorder (ASD). These educational programs for students with ASD focus on improving communication, social, academic, behavioural and daily living skills."

Research is conclusive and expert opinion universal that children with autism need autism specific early intervention if they are to have any prospect of participating in their community as adults. There is no point to early diagnosis if children with autism then have to wait years to enter an education program before anything is done about their autism.

Autism is a clinical diagnosis; it is a severe or profound disability. Without treatment, outcomes are especially poor. The research shows only 10% of people with untreated autism live independently as adults. Teachers are not trained or able to treat the communication, behavioural and social dysfunction that is the defining characteristics of autism. There is no evidence education programs are effective for autism unless children with autism are adequately treated for their autism to prepare them for education. Children with autism can access very little of the education they are given unless they are prepared for learning through intensive intervention prior to entering school. It is cruel to the children and their teachers to ignore this obvious conclusion.

Children with cancer or cystic fibrosis also need "early diagnosis and appropriate education programs" but we do not expect their teachers to manage and treat their clinical problems. Teachers are not trained to do that. Nor do we expect a child who is diagnosed with other health problems at 2 or 3 years of age to wait years until they enter school before anything is done for their condition. Why is autism singled out in this way?

Children with autism need a comprehensive program to treat their autism. In most cases, this needs to be supervised by a clinical psychologist specialising in autism. Instead, children with autism are offered generic therapy services. These mostly consist of physiotherapy, occupational therapy and social work. These services do not address the child's communication, behavioural and social dysfunctions and deficit that are the defining features of autism. Any therapies they receive tackles associated issues, but not their autism. This is like giving analgesic to a child for their cancer: it tackles the side effects of pain but does not address the core diagnosis. Even when speech pathology is provided, it lacks intensity and essential specialisation.

The problems are deep-seated. For example, ACT government agencies cannot attract enough staff to provide even generic therapy service for children with a disability. They have been unable to attract sufficient staff to consume their budget allocation. In NSW, the Ombudsman recently produced a special report showing even crisis service for children with disabilities are in crisis. I am inundated with complaints about the complete lack or profound inadequacy of autism services in all states and territories. The stories that have recently reached the media are just the tip of a very ugly iceberg.

The number of people affected by the lack of services is alarming. The government's answer to Senate Question 2397 quotes a highly credible source of data, the Western Australia autism registry, as recording 211 autism diagnoses in the years 2001 and 2002. If you compare this to the WA birthrate you will find the autism diagnosis rate is 8 per 1000 or 0.8% of children are now being diagnosed with autism in WA.

The Health Minister acknowledged that there were 45 autism diagnoses in the ACT in a single year. Were you to do the sums you would find 45 diagnoses in a single year is 1% of the birth rate for the ACT. Despite the need for early diagnosis, the ACT Health Minister said recently

"I am aware, as you point out, that the waiting list for autism assessment through Therapy ACT exceeds 120 clients. The waiting time for the person longest on the list is 20 months."

These figures resemble what is happening overseas. Though much of the data that has been collected can be a challenge to interpret, all Australian data points to this consistent pattern. At least 0.7% of Australian children are being diagnosed with some form of autism spectrum disorder.

There are over 30,000 Australian children with autism and their families needing help from the government. Despite this government's "third term agenda" you say in your letter "I am not able to advise you of any new initiatives at this time". Governments of our major allies have acted to create research centres and ensure children get treatment that helps them participate first in education and later in employment and their communities. At present, this government is not ensuring the rights under international law of children with autism to treatment, rehabilitation and education are met by the states.

I urge you to reconsider and to develop some new initiatives for autism. May 9–15 is National Autism Awareness Week: it will be an excellent opportunity to announce new initiatives.

Regards
Bob Buckley
Convenor - Autism Aspergers Advocacy Australia (www.a4.org.au)

22/4/2004

Editorial

Bon Voyage Nicole!

One of our A4 Editorial team is leaving us to go travelling overseas! Nicole leaves at the end of May and will return at the end of October. Part of Nicole's trip will be spent visiting the Scottish Autism Society and exchanging thoughts and ideas for the future. For details of Nicole's trip see the April profile. Good luck, Nicole! We look forward to hearing all about it when you return.

Member's contributions

Do you have a story that you would like to share? The A4 Update team is looking for member's stories about their personal experiences concerning advocacy, whether as an advocate for someone with an ASD or as someone who has an advocate. Stories about other issues concerned with ASD are also welcome. Please send your stories to edit@A4.org.au.

Volunteers

We are always eagerly looking for members to be our state correspondents for the A4 Update. This involves a regular round-up of state related ASD issues. This is a great way to become more involved in A4. If you are interested please contact us at edit@A4.org.au for further information.

DISCLAIMER

The information, articles, reviews, books and websites contained in this publication are presented in the spirit of keeping you informed and aware of developments in the field of autism spectrum disorder (ASD) and Asperger syndrome. They are not intended as a substitute for obtaining an individualised evaluation of your child and the advice of qualified health professionals trained in ASD. The statements made by various authors regarding products or services represent the views and opinions of those authors and do not constitute a recommendation or endorsement by the publisher.

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Letters to the editor

Yes … we still want your feedback. Tell us how we're doing, what you want more of, what you want less of, what's missing, etc.

Email us at edit@A4.org.au with 'your say'.

Dear Editor,

We are all aware of the significant gains that can be achieved by quality intensive early intervention. Furthermore the cost benefit to society of such programs is enormous, estimated at between $US 1-2 million over the lifetime of each child. These programs are available in most western countries with considerable government support: but not in Australia. Yet the Federal Government plans to spend $8 billion over the next 4 years on childcare. With an incidence of up to 1/100 children afflicted with autism the government should be spending a minimum of 1% of this money on Early Intervention Programs. The autism community of Australia needs to demand that funding less than $20 million annually for such programs is inequitable, unethical and financially lacking in common sense. In the lead up to the next Federal Government election let us make 'Autism 1/100 = 1%' a catch cry.

James Morton: AEIOU (Autism Early Intervention Outcome Units) www.aeiou.org.au

National/State Round-up

Queensland

National Autism Awareness Week Activities

The Ultimate Ladies (Long) Luncheon

Indulge yourself at the Ultimate Ladies (Long) Luncheon and help to raise awareness and funds for the northside respite house.

Date:	Wednesday, 12 May
Time:	12noon for 12:30pm start
Venue:	Gambaro Seafood Restaurant (Caxton Street, Petrie Terrace)
Cost:	Individual Ticket $68 Corporate Table $620

Guest of Honour
Her Excellency Ms Quentin Bryce, AC
Governor of Queensland

Comperes
Donna Lynch and Billy J Smith

Fashion Parade
NV Fashion
Napoleon Cosmetics
Giorgio Hair and Beauty

Major Prizes

- Stunning Jewellery Piece by Robert White Jewellers
- Sensational Sydney State of Origin III flight and accommodation Package from Expotel Executive Travel

Plus over $10 000 worth of prizes to be won and Celebrity Guest Appearances!

For further information contact please contact Nicole Seipel on [t] 07 3273 0000 or [e] nicoles@autismqld.com.au

Autism Queensland Wine

Buy a bottle of AQ Wine and give it to a friend!

Late last year Autism Queensland purchased cases of a 2001 Cabernet Sauvignon from Coonawarra (in South Australia). The wine comes labeled with our very own label containing information about They are available for $12 per bottle or $120 per case (of 12).

Please note: For people unable to pick these up, courier charges will apply.

For further information contact please contact Nicole Seipel on [t] 07 3273 0000 or [e] nicoles@autismqld.com.au

Bundaberg Autism Spectrum Disorder Support Group

The Bundaberg Autism Spectrum Disorder (ASD) Support Group will have static displays at the Visitors Information Centre in Bundaberg plus a manned information site for five days at Sugarland Shoppingtown. These visual displays will incorporate awareness displays, an Art Competition for the regions ASD children and the launch of an Autism Awareness ribbon (a green ribbon with gold stud and print). The ribbons will be sold to assist in raising funds in our local area and heightening awareness of ASD in our local community.

In addition there will be media coverage through the local Newspaper featuring an article providing Support Group information and some individual family input.

Contact: Marg Puxty on [t] 07 4155 2695 or [e] bundabergsg@autismqld.com.au

Autism Queensland Mackay Workshops

Tuesday 10 and Wednesday 11 May

Autism Queensland Training, Consultancy and Intervention Services will be providing a series of workshops in Mackay during National Autism Awareness Week. This series of workshops will examine the principles that underlie the diagnosis as well as the way factors unique to the individual person influence the picture. Effective strategies can be identified and implemented when these two areas are properly considered.

Day One Understanding ASD and Encouraging Desirable Behaviours

Day Two Improving Social Skills - Supplementing Explicit Teaching with Creative, Incidental On-The-Spot Approached

Contact: mailbox@autismqld.com.au

South Burnett Autism Support Group

Guest speaker Lionel Evans from Parent to Parent will be speaking at the South Burnett Autism Support Group on Friday 7 May to launch National Autism Awareness Week.

Location: Biscuit Pin (Catholic Church Building) Mary Street, Kingaroy

Contact: Jenny Lutz on [t] 07 4164 1107

ABIQ 2004 Autism Conference

May 14-15

Brisbane Technology Park Conference Centre

ABIQ in conjunction with Autism Queensland, Jesse.ka, and Disability Services Queensland present the 2004 Autism Conference.

The theme of "Reach for the Stars" reflects the belief that children with ASD have boundless potential to achieve. Presentations will cover a range of treatment approaches enabling families, carers and professionals to become better informed about how to assist the child with ASD.

The conference has so far secured the following world-renown professionals to deliver keynote presentations:

- Dr Tony Attwood When Dr Attwood is not traveling all over the world to present at seminars and conferences, he runs a diagnostic and treatment clinic for children and adults with Asperger¹s Syndrome.
- Dr Doreen Granpeesheh A renowned psychologist who founded the Center for Autism and Related Disorders, Inc (C.A.R.D.) in 1990. CARD is one of the largest organizations in the world providing treatment to children with autism, PDD and Asperger's Syndrome.
- Donna Williams - Born in the 60's, Donna was not diagnosed with autism until adulthood. She is an author of a number of best sellers, has traveled the world to speak at conferences and has worked with people affected by autism and Asperger¹s Syndrome.
- Dr Anthony Underwood A well-known biomedical pediatrician who has done a lot of work to help people with Autism. Dr Underwood operates his medical practice in Sydney.
- Stephen Shore - Diagnosed with 'Atypical Development with strong autistic tendencies' and nonverbal until age four. Stephen is now completing his doctoral degree in special education at Boston University. He is the author of the book "Beyond the Wall: Personal Experiences with Autism and Asperger¹s Syndrome".
- Amy B. Laurent - a pediatric occupational therapist and collaborator of the SCERTS Model in United States. The acronym "SCERTS" refers to Social Communication (SC), Emotional Regulation (ER) and Transactional Support (TS).
- Tracy Bester Tracy is the mother to four children, two presenting with Autism Spectrum Disorder. She is an international Autism consultant, founder of jesse.ka, and author of the book, "The Learning Curve Series".

Plus many more presenters.

For further information on the conference or the presenters visit ABIQ on www.abiq.org or [t] 07 3264 2582.

New South Wales

By Caroline Franks

The first of this year's Autism Association of NSW's quarterly publication Keynotes magazine has become available at ***www.autismnsw.com.au/publications/keynotes.asp***

Included is a summary of the Association's submission to the Federal Government's 'Review of Carer's Allowance and Child Disability Assessment Determination'. It asks that Autism remain on the list of recognized disabilities and the Asperger's Disorder, PDD-NOS and Atypical Autism be added. Recently the Association received funding from the Apex Foundation Trust for Autism and Rotary Clubs of Camden, Cobar, Dapto, Dee Why and North Sydney for a research project into evidence based outcomes of Early Intervention Programs for young children with Autism. The Association has also announced the findings and recommendations of an independent communication survey of parents and staff of the Association. It is really worthwhile reading and is available at ***www.autismnsw.com.au/about%20association/communicationsurvey.asp***

Wendy Lawson, currently on a speaking tour in the UK, reports that she is doing well on a gluten free diet after having been diagnosed with Coeliac Disease and that her new book 'Autism, sex and sexuality' is due at the publishers in July, 2004.

South Australia

Early intervention program for childhood autism finds friends

http://www.flinders.edu.au/news/articles/?fj02v15s02

International research has demonstrated that early diagnosis and therapy for children with autism greatly improves the effectiveness of treatment, and a new program run by psychologists at Flinders University is putting the principle into practice.

Flinders University's Early Intervention Research Program (EIRP) for Young Children with Autism employs behavioural techniques to reduce the severity of childhood autistic behaviours.

The program is headed by Flinders psychologist Dr Robyn Young, a specialist in childhood autism, who pioneered the development of a screening test that enables autism to be diagnosed in children as young as two years of age.

In recent weeks, two very different but appreciative audiences came to hear at first hand about the work and methods of the EIRP.

About 110 people, comprising parents of children with autism, health professionals and carers working in the field, attended a training seminar run by Dr Young which outlined the program's methods and techniques.

The EIRP team then hosted three follow-up workshops, each attended by about 30 people, during the rest of the week.

More recently, members of the Adelaide Crows met and mixed with autistic children and their families at the official handover of a donation made to the program by the AFL Players Charity Fund.

Crows players Mark Ricciuto, Brett Burton, Tyson Stenglein, Brent Reilly and Kris Massie signed autographs, posed for photographs and played with the children after handing over a cheque for $14,375.

Dr Young said the footballers' donation would enable six more children to become part of the EIRP.

"It costs us about $1500 for each child to be part of the program, so this funding has helped us greatly," she said.

The donation also covered the cost of a number of developmental toys, including a mini trampoline and an exercise mat.

"It has been a productive fortnight for the program," Dr Young said.

"The training day was especially fruitful as we were able to provide some assistance to parents, in the form of techniques and tips that we hope will enable them to communicate more effectively with their children.

Flinders Journal: March 1- 14, 2004

Disclaimer: http://www.flinders.edu.au/disclaimer/
Contact: wwwperson@flinders.edu.au

NSW Ombudsman tables report into DADHC

The NSW Ombudsman, Bruce Barbour, today released a special report to Parliament, which highlights the failure of the Department of Ageing, Disability and Home Care ('DADHC') to effectively support families at risk of giving up the care of their disabled children.

The report details the findings of an extensive investigation.

Mr Barbour said: "My investigation shows that

DADHC has failed to adequately support families to enable children with disabilities to remain in the care of their family."

"Many families who care for children with disabilities already face significant stress. The result of DADHC's ineffective intervention was that this stress was unduly aggravated."

The Ombudsman investigation found that the department's implementation of its policy for children and young people with disabilities demonstrated:

- lack of clarity about the department's role in supporting families in crisis;
- uncertainty about which sections of the department had responsibility for providing support;
- confusion about the respective roles of DADHC and the Department of Community Services ('DoCS');
- inconsistencies in DADHC's own policy requirements;
- inadequate guidance to staff about how to implement the policy;
- subsequent confusion about how services should be provided.

The Ombudsman said: "a major concern was that families were not able to get the services necessary to support them through difficult times".

The investigation found:

- confusion about how to obtain access to services;
- no clearly defined decision making process about access to services;
- a fragmented and poorly co-ordinated service system
- no clearly defined avenue of appeal where services were denied or considered inadequate

The Ombudsman investigation also found that, for children with disabilities who were not able to remain living with their families, service arrangements were often inadequate.

"These children were not provided with the same safeguards as children who enter care through the child welfare system. "

The Ombudsman said: "DADHC has responded to our investigation in a positive way by developing an action plan and establishing a task force to address the problems we have highlighted".

Strategies within the action plan include addressing staff training needs, implementing an effective system to deal with requests for support, enhancing service access and coordination, and improving the range of available services.

"The key to the department's improvement in this area will be effective implementation of its action plan. It is an ambitious plan and we will be closely monitoring the department's progress over the coming year." Mr Barbour said.

14 April 2004

Biennial Australian Autism Spectrum Disorder Conference

Autism Spectrum: Pathways To Understanding

Autism Association ACT

Friday, 1 October - Sunday, 3 October, 2004
Venue: Rydges Lakeside Canberra

The conference will be preceded by a day of focused workshops on 30 September, also at Rydges Lakeside.

Keynote Speakers

Professor Christopher Gillberg
Dept of Child and Adolescent Psychiatry
(Göteborg University, Sweden)

Dr Jeannie McAfee
[Author: *Navigating the Social World*; see Dr McAfee's internet site here.]

Dr Tony Attwood
[Author, trainer and diagnostician; see Dr Attwood's internet site here.]

The conference website is http://autismact.homemail.com.au

April Profile

Our April Profile is on Nicole Seipel. Nicole is the other half of the A4 Editorial team responsible for bringing the A4 Update to the readers each month. She kindly agreed to be 'profiled' for this issue of the Update.

NAME Nicole Seipel (pronounced Sigh-pul)

BORN 27 years ago in Brisbane

LIVES Brisbane

FAMILY Partner Luke; furry white children: Oliver and Lotus

INVOLVEMENT WITH A4 Signed up last year to receive the update for work purposes then answered a call for volunteers not long afterwards.

OTHER ORGANISATIONS Currently working as the Communications and Fundraising Officer for Autism Queensland.

DREAMING OF More funding for people with disabilities.

LISTENING TO Talk back radio – I think it's a sign I'm getting older!

READING "Europe on a Shoestring" – a Lonely Planet guide book for a cheap European holiday.

RELAXING I believe that's something people occasionally do???

EATING Fasta Pasta → Spinach and Ricotta Ravioli Alla Panna – delicious!

LIKES Spending time with my family, playing with my children (the furry white ones!) and seeing the successful culmination of a project (very rewarding).

DISLIKES Narrow-minded people and the word NO!

IDEAL WEEKEND Spending time with family and friends, working in the garden, watching the Broncos win, being busy, etc…

LAST HOLIDAY A week and a half in Melbourne … but more importantly …

NEXT HOLIDAY 4½ months overseas: First stop is London then onto Scotland (where I'll be visiting with the Scottish Autism Society) then to Croatia for some volunteering (Island Conservation) then onto Russia (more volunteering at a Russian Summer Camp) then a whirlwind 8 week tour of 11 European countries. You'll see my report about the UK Autism societies in an Update when I return later this year.