A4
UPDATE
Autism Aspergers Advocacy Australia

June 2004
Issue 3

Feature: a petition

Dear Reader, I am the author of a petition for a National Autism Register and Voluntary DNA Database and I have been asked to write why I chose these issues to petition for.

As a mother of a severely autistic child I would like to see him live independently one day, to love and be loved and to reach his full potential. I feel this involves providing my son with the best possible opportunities for growth based on evidence-based interventions and therapies. The government will only fund the determination of best practice if voters persuade them to do so.

Firstly, I became aware that a large amount of money was going to be made available for scientific research on mental disorders and I felt that some of that money should be spent on autism research. Not being an autism expert, I consulted by phone, email or in person several well-known figures in autism treatment, research or diagnosis for their opinion as to what would be worthwhile petitioning for. They include Professor Bruce Tonge, Associate Professor Averil Brereton, Dr. Natalie Silove, Professor Max Bennett, Dr. Katrina Williams, Professor Stewart Einfeld, Dr. Trevor Clarke and Professor Peter Schofield. I also sought the opinion of Mr. Bob Buckley of A4 and Dr. Elizabeth Sheedy of Leaning to Learn, Sydney.

Two main ideas were mentioned to me. The first was to set up guidelines to help people find good quality information on autism treatments and interventions on the World Wide Web. I felt this could not be done until adequate research on the effectiveness of the available therapies or interventions is preformed. I had found proponents of at least fifty different therapies or interventions, which argue that their treatment is effective, sometimes based solely on testimonial and anecdotal “evidence”. Surprisingly, I discovered that the Children’s Hospital at Westmead had submitted a research proposal to examine the effectiveness and limitations of many of these therapies and early interventions. The National Health and Medical Research Council rejected this proposal.

The second idea was to petition for general funding for Autism research. Autism was first labelled in 1943 and yet at the beginning of the 21st Century we still we still don’t know the cause, how to cure it, how to best treat it, how to screen for it or what environmental factors are significant. Initially I wanted to petition for funding to implement a survey to find out what scientific research, people living with autism, consumers of ASD services and parents and carers of ASD people feel would be beneficial. However, I became aware that a new centre, the Brain and Mind Institute (BMI) had been formed in Sydney to study disorders of the brain and mind. I believe some of its activities will be primary research, clinical services and also to serve as a central body for the collection and exchange of information at the National and International level. I was disappointed when told by the Head of this new institute, that BMI will not be researching autism but looking at conditions including Alzheimer’s, Parkinson’s and depression. This is because they have a significant economic and social burden on the Australian Community and because the Prime Minister’s Science, Engineering and Innovation Council hope to ensure funding is directed towards lessening a blow out in health care costs and welfare payments due to life-long debilitating disorders which result in personal suffering, costly care, long-term unemployment and therefore erosion of the tax base.

Finding the true incidence and prevalence of autism or ASD's is an important first step in determining the impact of autism on individual families and the Australian Community as a whole. Having a national repository of research and clinical data would also provide the raw data necessary to support local research as well as aiding international research efforts. National Immunization, Cancer and Pap Smear Registers already exist that offer invaluable information to individuals, researchers and clinicians.

I am interested in the Voluntary DNA Database for my daughters' sake as we are concerned about the potential for autistic grandchildren. (Consultation with a leading Clinical geneticist revealed that my husband and I have a one in six chance of having another child with autism). A DNA Database may ultimately lead to understanding the causes of Autism, inform treatment and perhaps even provide a cure for severe autism.

Although I would like to cure my son's autism, I do not mean to infer that autism precludes him from contributing to society or that it makes him less valuable than other people. My concern is with people like me who are in agony over the fact that their child appears locked out from the world in which they live and who are clearly frustrated by things they do not understand and that they are powerless to help their children remedy.

A Voluntary DNA database would give researchers the opportunity to invite families to participate in long-term follow-up studies as new evidence comes to hand.

Lastly, the reason why I chose petitioning as a form of lobbying is because I have had success with it on several occasions both at the local council and federal level. For example, some years ago I wrote a petition for funding for guidelines for the management and emergency procedure of asthma in the under 5's. With the help of various peak bodies and interest groups, I was lucky enough to have my petition taken notice of and now every long-day care centre, kindergarten and pre-school in Australia has access to these guidelines.

Sincerely,
Caroline. (Mother in distress)

You can download Caroline's petition from www.a4.org.au/petition.

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An Audience with Autism

Picture the scene, hundreds of white chairs lined up on the grounds of parliament house. A photo attached to each chair, a photo of someone with ASD. Hundreds of people represented by white chairs, the chairs themselves representing the sitting of parliament and the silent pleas of acceptance and understanding.

On ***Thursday 30 September***, A4 will be staging an awareness event **'An Audience with Autism'** to coincide with the Biennial Autism Conference in Canberra. We will be walking to Parliament house with invited Parliamentarians and the Autism community. We will walk to where the sea of white chairs will be set up to represent those of us that can't be there on the day.

Even if you can't make it to Canberra, you can still be represented. To help with the cost of the chairs, you are asked to sponsor a chair for your loved one with ASD/Aspergers for $10. Their name, diagnosis, age, state/suburb and photo (optional) will be placed on the chair for the politicians and the world to see. Families, friends, relatives, teachers — ANYONE can send a picture on behalf of someone with ASD/Aspergers to be placed on a chair.

Having hundreds of chairs lined up in front of Parliament House will raise the profile of Autism and give you a chance to be there in spirit.

We also need volunteers to:

- Give your elected politician an invitation to join the event.
- Get a group together in your local area to be there with us on the day.

Details of what to do to join this fantastic Autism Awareness event will be on the website www.a4.org.au/awarenessevent soon. Or contact your local Autism society, support group or write to An Audience with Autism – attn: Kelley Harris PO BOX 524 Traralgon 3844 for more details.

We want everyone in Australia to know we are here, so lets stand up (or sit down!) and be counted.

Convenor's message

Dear A4 member,

Please join me in congratulating all those people who were involved in Autism Awareness Week (AAW). The activity around the country was considerable. This edition of A4 Update contains reports from around the country.

This year A4 asked members to be part of their regional or state activity for AAW. We were not able (not really ready) to coordinate a national event or campaign. I would like to see A4 promote a national component to AAW next year.

Please allow me to put my personal view on awareness and the nature of what we call the autism spectrum. Naturally, most of us have a limited experience of the autism spectrum. This colours our view. The nature of ASD organisations is to focus on disorders attributed to the spectrum. It is important to remember that some of the behaviour we notice is simply different rather than disordered. Some different behaviour is empowering: for example, the ability to focus intently and persistently can be an academic strength. Autistic differences enrich my world.

When different behaviour is dysfunctional to an extent that requires clinical intervention, it can be considered a disorder. The DSM-IV classifies Pervasive Developmental Disorders (also known as Autism Spectrum Disorders) on Axis I Clinical Disorders (they were on Axis II in the DSM-III). Technically, a DSM-IV diagnosis of any PDD (or ASD) should only be given when those doing the diagnosis believe clinical intervention is required. (*I don't know what the ICD-10 says about such issues*).

Some behaviours that impact on a child's learning, social interaction, anxiety, etc. at school are being described as autism-related. Some school authorities require an ASD diagnosis before a child can access essential (non-clinical) education assistance and support. There are signs that the community has responded by providing ASD diagnoses where support is critical, but clinical intervention may not be necessary. I believe this situation is causing confusion.

My preference would be that the term 'disorder' be used where dysfunctional behaviour requires clinical intervention. A different term, such as 'autism spectrum condition (ASC)', could be used where assistance and support (not of a clinical nature) is required in education, employment, living and community settings. And a different term again could be used where it promotes or assists appreciation and understanding of difference. Of course a person with ASD, as I've described it above, also needs support, assistance, appreciation and understanding … as well as clinical intervention. I would welcome debate on these issues.

The previous A4 Update contained a copy of the letter sent to The Hon. Trish Worth MP, Parliamentary Secretary to the Minister for Health and Ageing. We received a response dated 27 May 2004 (download it from www.a4.org.au/documents/TW040527resp-lores.doc). Again, Ms Worth in her response ignores the issues raised in our letter:

- The lack of expertise in the Health Department, and the consequent lack of action or even concern about ASD from health administrators and government.
- For most Australian children with ASD, diagnosis is not followed by the essential treatment for their ASD.
- Education is not sufficient to meet the clinical needs of children with ASD.

However, I met recently with an advisor to the federal Health Minister who invited A4 to present a proposal for early childhood. The policy group is in the process of preparing a high level proposal.

Mr Latham, the Labor leader, said in his budget response that school leavers would be "learning or earning — no third option". It seems to me Labor's position also ignores people with ASD. As described, Labor's policy leaves no option for people with ASD when they leave school. They have no policy for children with ASD. There is a suggestion they will develop a policy before the coming election.

Some new and hopefully compelling evidence for government is emerging that change is needed. This year FaCS is granting the Disability Support Pension (DSP) to 21 people who are identified with Autism or Aspergers syndrome for every 10,000 people who reach 16 years of age, the age one becomes eligible for DSP (FaCS indicated there may be more people as people do not always record their diagnosis). The number of people with autism or AS being granted the DSP is more than double the number of people FaCS previously thought had ASD. Mostly, people with autism or AS being granted DSP are 16 years of age and almost all of them are under 20 years of age. The outcome from existing services is that FaCS accepts their learning has been limited and doubts they will never be employed.

At present, ASD is the most important issue in my life. There is an election coming up and neither of the major parties, as yet, has a policy relevant to ASD. At present I could not vote directly for either of the parties who are likely to form government after the election. I will be writing to the major candidates in my electorate, and senate candidates for the ACT (my state), inviting them to win my vote by telling me what they will do for people, especially children, with ASD. When I've written my letter, I will invite my friends and relatives to send similar letters to their candidates. I know some of them care enough to want to help me. I invite you to do the same.

Regard,
Bob Buckley, Convenor (convenor@a4.org.au).

Angels with Us Everywhere

Written by Soraya van Eyk

Due to complications with the birth of my first child, the doctor decided a scheduled caesarean for the birth of my second child would be safest for my baby and me. It was a strange feeling, having an appointment to have a baby. Nevertheless, the next day was going to be the last full day my son had me all to himself. So I thought …

On Wednesday 25th July 2001, at 5am I experienced a twang in my stomach. Fifteen minutes later another twang, could it be that I was having contractions. Another ten minutes went by and again a twang in my stomach but this time stronger than the first two. By 6.30am I was telling my husband (who was preparing to go to work) he could have the day off, we were going to have the baby.

I was booked in for a caesarean the next day and therefore not prepared for the early birth. Babysitting arrangements needed to be changed. (Enter Angels 1 & 2) My aunty and uncle lived nearby, so they looked after my son until my parents collected him.

At 3.05pm I gave birth to a 7lb 4oz beautiful baby girl. The tears of elation flooded down my face. My daughter was healthy. I had a pigeon pair, and experienced a natural birth (thanks to Angels 3, 4, 5, & 6 – the midwives and my sister-in-law), what more could a mother want. After the birth I still had complications and needed to be rushed to the operating theatre. Having trouble passing my placenta I began to haemorrhage and needed a blood transfusion. Thanks to the wonderful surgeon and theatre staff (the "Saviour Angels") my children still have their mother.

With these blessings in mind, it horrifies me to see the social and moral principles some parents are teaching their children. After attending our local playground with my now 2½ year old daughter, I left with mixed emotions. My daughter was trying to push past another young child in a tunnel to get to the slide, without noticing my attempts to get her to "wait". Unfortunately, my daughter pushed the young child out of the tunnel and onto the platform causing the young child, naturally, to cry.

I apologised for my daughter's actions to the child's mother, to which she replied my child should not be in the playground. My disbelief prompted me to explain the reason my daughter doesn't understand the word wait is due to the fact that she is Autistic. With a very cold and abrupt tone in her voice she went on to tell me that was even more reason for her not to be in the playground.

With tears flowing down my checks I picked my daughter up and went over to the other equipment. Here I met a "True Angel". A lovely lady whose name I don't know and whose face I have never seen, came over and introduced her twin daughters to us, encouraging them to play with my little girl. It was obvious she had just witnessed the inexcusable behaviour of the other women. No words of the incident were spoken between us. The remainder of our time spent at the playground was enjoyable, thanks to the lady whose name I still don't know but whose face I will never forget.

Autism Awareness Week
Victoria

Full size pictures are available for download at www.a4.org.au/documents/vicnaaw04a.jpg and www.a4.org.au/documents/vicnaaw04b.jpg.

National Autism Awareness week in Victoria reached new heights this year with the birth of a state-wide awareness campaign aimed at politicians. "Pin a Pollie" (PAP) was the brainchild of Penny Hackett, grandmother of Joshua Hackett who currently attends Irabina Childhood Autism Services in Bayswater. Penny came up with the idea during a public meeting when she and her husband pinned the attending politicians with the pins they themselves had been wearing.

'Pin a Pollie' was launched on the steps of Parliament House on Wednesday 12th May 2004. The inaugural campaign was a major success, with over 60 politicians participating at either a local electorate pinning, on the steps of Parliament House or both. The campaign received media coverage on Channel Ten news and ABC radio that night which was an enormous feat with the Federal Budget being passed down the night before. There has also been media coverage at each respective local pinning. In the month of May, Autism has been mentioned in Parliament's Hansard a total of thirteen times and the PAP campaign seven times. This is absolutely fantastic for Autism Awareness.

Following the inaugural pinning, a morning tea was held in Parliament House where 30 MP's and 40 families and their children attended. Victor Perton (Shadow Minister for Education – Member for Doncaster) spoke briefly about his affiliation with Autism and his support for PAP. Penny Hackett spoke about how she came up with the idea of PAP and Helen Shardey (Shadow Minister for Community Services – Member for Caulfield) spoke about her recent trip to America and how she visited Autism centres. Meredith Ward (President – AFSA) spoke first hand about her experience with her son Grant, a very moving speech that left two MP's in tears. Casey Brown 11 years old and his brother BJ Brown 7 years old who are both on the spectrum thanked everybody for attending and supporting Autism Awareness. Lastly, Bob Stensholt (Member for Burwood) also wanted to acknowledge everyone for attending as he has a 14 year old daughter who is also on the spectrum.

With such a successful event in mind, the Autism community needs to grab hold of PAPs shirt-tails and make the most of the awareness it has established. Now is the time to keep the ball rolling, ensuring the government and our community continues to learn about our children, their lives and their disability. Let's remain strong in our stand to get our message heard so that when PAP goes national in 2005, Australia is behind us.

We would like to thank everyone involved in making Penny Hackett's idea a reality. We would also like to congratulate all politicians who participated in PAP, strengthening the relationship between themselves and the Autism Community.

Lastly, PAP could not have happened without the support of AFSA and Autism Victoria. Thank you for everything, and to Brian Carr who donated his time to take the Photographs.

'Pin a Pollie' Steering Committee
Soraya van Eyk, Meredith Ward, Anita Harvey & Sheriden Hackett

AUTISM AWARENESS WEEK AT OLGC SCHOOL

Written by Jo Heard

Autism Awareness was held nationally during the month of May. The children at Our Lady of Good Counsel School were fortunate to be able to participate in an event in which they learned a little about Autism then drew pictures and wrote stories which were presented to Mr Andrew McIntosh (Member for Kew) at a special assembly on Tues May 18h.

Autism Spectrum Disorder (ASD) is the term used to describe the range of developmental disabilities on the autistic spectrum. It affects between 1 in 160 –200 people. ASD is a lifelong condition that affects a person's communication and social interaction skills. People with ASD may have difficulty processing what the sense (see, hear, touch, taste, smell, movement) which may result in unusual and sometimes challenging behaviours. Because people with ASD may not physically appear to have a disability their behaviour is often misunderstood.

ASD also affects a child's learning style and ability, yet they are capable of a great deal. Community support and consideration of their individual needs will help them achieve their full potential.

Assistant principal Mr Brian Grace, a teacher with experience teaching children with ASD addressed the school assembly in the week leading up to Mr McIntosh's visit. He described a child with ASD as similar to being left handed in the world where most of us are right handed.

OLGC prep student Dominic has ASD. He attends the school one day per week with the assistance of an integration aide, and the other four days are spent at a specialist autism school. The children were able to hear and learn something about Dominic's disability and how it affects his social understanding. Mr Grace spoke of tolerance and fairness within our community and how important it was to help Dominic negotiate his world.

The children spent time writing short stories and drawing pictures about ASD in our community. Principal Mr Gilbert Keisler presented these to Mr Andrew McIntosh State Member for Kew at a special assembly on Tuesday May 18th. Mr McIntosh addressed the children stating that should all respect each other regardless of differences such as ASD. Mr McIntosh told the children that he would take all their pictures and stories back to Parliament House to share with his colleagues.

This small Autism Awareness event showed how Our Lady of Good Counsel School is a great place for Dominic and other students affected by ASD. The caring and tolerant approach within the community is reflected by Dominic's happiness and enthusiasm to attend school.

ACT

In the ACT Autism Week started a few days early with the launch of our new autism awareness poster, *Autism If in doubt....* and a pamphlet *For Kids' Eyes Only* on ASD for primary school aged children on May 5th. Junee Waites, author of *Smiling at Shadows*, who officially launched these items, gave a heartfelt talk on her experiences with her son, Dane. Those present were delighted to talk to Dane, Junee and her husband during the supper afterwards.

During Autism Week itself the Association collaborated with our local government therapy provider, Therapy ACT, to bring Kate Strohm from Siblings Australia to the ACT. Kate spoke to a large group of parents on the Thursday evening and then presented a more formal workshop to approximately 40 service providers the following morning. As many members have requested discussions on sibling issues we were pleased to be able to meet this need. Now we must organise a group for the siblings themselves!

In addition to the Kate Strohm events the Association had displays in several shopping centres around Canberra as well as providing materials on ASD to a couple of schools, with designated ASD classes, who were running an Odd Sock Day to raise awareness and funds within their school. A number of schools followed our request to put a short article (which we supplied) into their school's newsletter that week. Our final awareness project for Autism Week took place at the Paediatric and Allied Health Meeting when one of our members spoke briefly about the Association and its new publications.

The ACT Association wrote a short letter to our politicians describing the autism spectrum including Aspergers syndrome. We provided each of them with a pin and asked them to wear it during the week.

Tasmania

Autism Tasmania has revolutionised their meeting procedures in a move which addresses the time commitment of state-wide meetings. This is a move which has enormous potential for enabling isolated people to participate in decision making and advocacy activities. Cheryl Scott, secretary of Autism Tasmania, says that we have been able to access Telehealth facilities at each of the 3 main regional hospitals in Tasmania (Launceston, Hobart and Burnie) in order to conduct our meetings. It is hoped that we will be able to access other Telehealth facilities, say on the East and West Coast within 6 months.

Telehealth facilities currently include some fairly high tech hardware including dual plasma screens and high speed internet connections which enable people at multiple sites to see and hear each other in real time. We can also view documents via a document camera and can adjust camera angles locally and remotely as required (ie I can swing or zoom another site's camera around if I need to). The equipment is quite user friendly, which is a bonus.

We have been granted access for a set time once a month from 5 - 6.30pm, which means we don't have to put aside long periods for travelling say to Ross or to each region every 6 weeks or so, - and because the meetings are monthly we can follow up issues more rapidly.

We have found that the chairman now has a more demanding task because of the slight time lag we have encountered between sites. That has been a good thing in some ways, because it has forced us to make our meeting procedure tighter and we stick to the agenda better. There have been occasions when I have been able to get the minutes out the same night as the meeting - which has been very impressive and would not have happened the old way.

So far the benefits have been numerous:
Family friendly meetings (since we are all volunteers)
More efficient use of meeting time (less chat)
More frequent meetings (able to be more proactive)
More interest from other members in attending (it was only the die-hards before)

Cheryl believes that the majority of committee members feel that the teleconferences have been beneficial. This is very exciting for me, because as a person with Asperger Syndrome, I found the face to face weekend meetings very taxing. I live in a small, isolated town and I am looking forward to the day when our hospital comes online so that I can enjoy meeting from a quiet venue near my home.

Geraldine Robertson

Qld

NAAW 2004

There was a stark contrast in activities from a majority of the autism groups in Qld compared to those activities in 2003. The media attention particularly within Brisbane was apparent and constant. All autism groups getting the chance to raise the profile of autism through various media.

As an initiative of many of the autism groups…a brochure “What is Autism” was created. This is being distributed throughout Qld via many avenues. This was supported by Autism Queensland, AEIOU (Autism Early Intervention Outcomes Unit) and Autism Behavioural Intervention Qld. Tracy Bester (Autism Consultant) of the recently established Autism Australia organization managed many TV, radio and print interviews in her quest to raise the profile of autism.

Autism Queensland, The Hon. Pat Comben (CEO) and the Northside Autism Respite Events Committee hosted for its second year, a fashion parade. Over 250 people attended the function with Guest of Honour Ms Quentin Bryce, Governor of Queensland. Also local sporting icons … the Bronco’s rugby league players were in attendance. It was an exceptional event with rave reviews about the Ultimate Ladies (Long) Luncheon.

Autism Behavioural Intervention Queensland (ABIQ) hosted The 2004 Autism Conference. The event was supported financially by Disability Services Queensland and Autism Queensland. The conference gave Qld parents and professionals the opportunity to hear national and international speakers in the field of autism. The theme of the conference was “Reach for the Stars”. This theme reflects the belief that children with autism have boundless potential to achieve. The conference was a runaway success for ABIQ and attracted over 450 delegates. It attracted presenters from all over Australia and the USA. The presentations were video taped. Anyone wishing to obtain a copy can visit www.abiq.org or contact ABIQ by phone on (07) 3264 2582.

ABIQ hosted their inaugural ball “Reach for the Stars” on the last day of the conference. Carrying on the theme from the conference the ballroom dazzled with stars galore. 185 guests including parents, friends, businesses and corporations were all there to show their support of ABIQ. The evening was a fun filled night. On a more serious note, it gave ABIQ a chance-through the presentation of a short video- to let people learn more about how a child with autism is affected. The auctions were more than successful in raising the monies to fund ABA kits for the children -- particularly those in regional and rural Queensland. The event was also captured in the social pages of the Sunday Mail.

As a lead up to National Autism Awareness Week and as a means to get the community involved, Autism Australia launched a state-wide competition, referred to as the ‘Signature Campaign’ for all schools in Queensland. For schools to be eligible to nominate they needed to provide answers to the question - “What is Autism?” in 25 words or less; and other initiatives to indicate their school to be autism-friendly. Three schools received prizes from a large prize pool. Tracy states that the "Signature Campaign" has a twofold purpose to raise – funds for establishment and maintenance of parent training centres and secondly awareness of autism throughout Australia.

Aspergers Syndrome Support Network showed their support of NAAW by partaking in an exhibit at the conference.

Autism Queensland and Autism Early Intervention Outcomes Unit were featured in the 7.30 report, discussing the serious issue of the need for young children to be accessing quality early intervention. The 7.30 report also featured Bob Buckley – convenor of A4.

Queensland are hoping to continue raising the profile of autism through various channels for next year and offering vehicles in which the community can show their growing support.

ASD in the media

The media has given ASD unprecedented press in recent times. This includes:

- Several papers reported that **'Michelangelo** may have been a Renaissance "Rain Man"'
- **The WA edition of the Weekend Australian** reported (8/5/2004) Education Minister Alan Carpenter concluded that a caged enclosure had been a necessary and appropriate way to discipline 12-year-old student.
- **Girlfriend** magazine.

  The June edition has some wonderful stories about siblings who have a brother/sister with Down Syndrome and another who has a sibling with autism. There's also a story in there about a young girl with epilepsy. Suddenly it can be cool to read about all of this stuff.

  Thanks **Girlfriend**. It costs $5.00 and there's a heap of other supportive stuff in there.
- **Dr Catherine Skellern** told the press her colleagues exaggerate autism (see below).
- There has been an avalanche of press interest in **Jason and Daniela Dawes.** A4 has not been able to get a copy of the judgement yet. Reports in the media say services in NSW were a subject of considerable criticism.
- The June edition of **Woman's Weekly** monthly has a story headed **"the Anguish of Autism"** on pages 134-140.
- The **ABC 7.30 Report** aired a story on 26/5/2004 that originated in Queensland. If you missed it, you can read the transcript at http://www.abc.net.au/7.30/content/2004/s1116714.htm. The story is mainly about the lack of early intervention in Queensland. The efforts of Dr James Morton and AEIOU in starting a private evidence-based early intervention centre are mentioned. The transcript contains some quotable quotes.

Queensland: state of exaggeration

Dr Catherine Skellern from Queensland told the press "58 per cent of the doctors admit they've been exaggerating the diagnosis of autism in children". You can read the transcript of the ABC Radio National story at www.abc.net.au/worldtoday/content/2004/s1110536.htm. There were similar reports in numerous papers around the country.

The DSM-IV says the purpose of diagnosis includes helping treat mental disorders. Dr Skellern says the diagnoses being given are precisely for this purpose; so one wonders how this is "exaggeration". So far there is no sign Centrelink has taken seriously Dr Skellern's accusation that most of her colleagues are engaging in medical fraud.

The Royal Australasian College of Physicians has not provided A4 with a copy of Dr Skellern's paper presented at their annual conference. We expect Dr Skellern and/or the press has exaggerated her results.

In Queensland, the Hon. F.W. Pitt, Minister for Communities, Disability Services and Seniors, on the 12 May 2004 made a speech for Autism Awareness Week. He said:

> "The most recent snapshot figures indicate that around 10 per cent the Queensland population has some form of Autism."
> and
> "While financial support and assistance is obviously a necessity for those with Autism, there is something that is even more important—understanding."

We believe the Minister is exaggerating the prevalence of autism. He has not responded to our letter.

Similarly, the Minister exaggerates the benefits of "understanding"; perhaps, because he expects it won't affect his bottom-line. Is there evidence showing that "understanding" of people with autism is "even more important" than approaches more usually advocated by parents and professionals? A4 still believes effective early intervention and ASD-specific services are the most important priorities for children with autism.

Research

The Genetics of Autism

By Rebecca Muhle, BA, Stephanie V. Trentacoste, BA and Isabelle Rapin, MD
PEDIATRICS Vol. 113 No. 5 May 2004, pp. e472-e486
May 6, 2004, 01:42

http://www.child-neuro.org.uk/artman/publish/article_61.shtml

Autism is a complex, behaviorally defined, static disorder of the immature brain that is of great concern to the practicing pediatrician because of an astonishing 556% reported increase in pediatric prevalence between 1991 and 1997, to a prevalence higher than that of spina bifida, cancer, or Down syndrome. This jump is probably attributable to heightened awareness and changing diagnostic criteria rather than to new environmental influences.

Autism is not a disease but a syndrome with multiple nongenetic and genetic causes. By autism (the autistic spectrum disorders [ASDs]), we mean the wide spectrum of developmental disorders characterized by impairments in 3 behavioral domains: 1) social interaction; 2) language, communication, and imaginative play; and 3) range of interests and activities. Autism corresponds in this article to pervasive developmental disorder (PDD) of the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* and *International Classification of Diseases, Tenth Revision*. Except for Rett syndrome—attributable in most affected individuals to mutations of the methyl-CpG-binding protein 2 (*MeCP2*) gene—the other PDD subtypes (autistic disorder, Asperger disorder, disintegrative disorder, and PDD Not Otherwise Specified [PDD-NOS]) are not linked to any particular genetic or nongenetic cause. Review of 2 major textbooks on autism and of papers published between 1961 and 2003 yields convincing evidence for multiple interacting genetic factors as the main causative determinants of autism.

Epidemiologic studies indicate that environmental factors such as toxic exposures, teratogens, perinatal insults, and prenatal infections such as rubella and cytomegalovirus account for few cases. These studies fail to confirm that immunizations with the measles-mumps-rubella vaccine are responsible for the surge in autism. Epilepsy, the medical condition most highly associated with autism, has equally complex genetic/nongenetic (but mostly unknown) causes. Autism is frequent in tuberous sclerosis complex and fragile X syndrome, but these 2 disorders account for but a small minority of cases.

Currently, diagnosable medical conditions, cytogenetic abnormalities, and single-gene defects (eg, tuberous sclerosis complex, fragile X syndrome, and other rare diseases) together account for <10% of cases. There is convincing evidence that "idiopathic" autism is a heritable disorder.

Epidemiologic studies report an ASD prevalence of ~3 to 6/1000, with a male to female ratio of 3:1. This skewed ratio remains unexplained: despite the contribution of a few well characterized X-linked disorders, male-to-male transmission in a number of families rules out X-linkage as the prevailing mode of inheritance. The recurrence rate in siblings of affected children is ~2% to 8%, much higher than the prevalence rate in the general population but much lower than in single-gene diseases. Twin studies reported 60% concordance for classic autism in monozygotic (MZ) twins versus 0 in dizygotic (DZ) twins, the higher MZ concordance attesting to genetic inheritance as the predominant causative agent. Re-evaluation for a broader autistic phenotype that included communication and social disorders increased concordance remarkably from 60% to 92% in MZ twins and from 0% to 10% in DZ pairs. This suggests that interactions between multiple genes cause "idiopathic" autism but that epigenetic factors and exposure to environmental modifiers may contribute to variable expression of autism-related traits. The identity and number of genes involved remain unknown.

Please download the article for the rest of the technical discussion.

The early detection of autism in clinical practice

By Susan E Bryson PhD, Lonnie Zwaigenbaum MD, Wendy Roberts MD
Pediatrics & Child Health April 2004, Volume 9, Number 4:219-221
May 8, 2004, 14:28

... *available online at* http://www.child-neuro.org.uk/artman/publish/article_64.shtml

Letters

Dear Editor,

I am writing a belated response to an article in your February edition. Lenny Schafer has published his Sound of Silence ditty quite widely. It is probably best known for the pain and anguish he caused autistic adults who do not appreciate autism being labelled a "cancer" and an "insult". Mr Schaffer's response to those who dared to try and explain their perspective was less than respectful of a different point of view. If you substituted the name of any other condition for autism, and published this ditty, you would probably be accused of discrimination. Try the words "Deafness like a cancer grows" and you would have the wrath of the deaf and hearing impaired community to contend with.

While I acknowledge that the hurdles in life faced by people with profound disabilities are immense, and so is the effect on a family, the fact is that many of us like who we are and feel that some of our best characteristics are those shaped by autism. I sincerely hope no children or teenagers were exposed to those words. Many would find them deeply wounding, particularly as many teenagers are fully aware that society often finds them tiresome and worthless. To add "cancer" and "insult" to something that has such an influence on personality is hard to cope with.

You might ask what this has to do with advocacy. It has everything to do with it. I have sat here for some hours tonight with feelings of hurt awakened. I have thought about the savagery of Lenny Schaffer's response to autistic adults who told him how they were hurt by his words and I have been afraid to say anything in case I attracted a similar response from the editorial committee. It is now 5 am, and I have decided that my self advocacy for the week is to tell you how many of us feel, because if I don't, you will never know, and you will perhaps inadvertently perpetuate feelings of worthlessness in other autistic adults and even in some of your children.

Regards
Geraldine Robertson

Policy Group

The A4 policy development subcommittee is working on our interactions with federal politicians, departments and organisations. Following a meeting with one of Mr Abbot's advisors, A4 was invited to develop a proposal for government on health issues for children with autism before school age.

There have been some initial informal discussions with FaCS about employment, disability support pension, measuring outcomes for people with ASD and long-term goals.

The policy group approached the paediatricians in the Royal Australasian College of Physicians for discussions.

New A4 Update Team

The old team is moving on. Nicole is going overseas for a while. Jo Heard, who has been managing Bob and acting as critic and conscience, is taking a well deserved break from (well, at least reduction in) A4 activities. Bob Buckley wants to concentrate on policy issues.

The new team would firstly like to say a big hello to all our members. We are looking forward to the challenge of producing future Updates for A4. If members have suggestions on content for the Update, now is the time to speak up. Please email us at edit@A4.org.au

Members of the new team are: Vic - Anita Harvey, Jo Heard, John Counsel, ACT - Bob Buckley, NSW - Seana Smith, Robyn Steele, Amanda Sheppeard, Qld - Dee Brough, Lyn Bewley, Ken Williams, Helen Curtin, SA - Michelle Goldfinch and TAS – Geraldine Robertson.

International VSA Arts Festival

Name: Tim Sharp
Origin: Queensland, Australia
Category: Drawing, Young Adult

Biography: "No one could have imagined that a three-year-old boy who was given such little hope would end up going on a journey that would take him so far and give him so much happiness, all because he dared to draw and use his imagination." — Judy Sharp (Tim's mother Tim Sharp is a 15-year-old artist from Queensland, Australia. At the age of three, he was diagnosed with autism and his family was informed of a dismal prognosis. Through his artwork, Sharp has proven every prediction wrong. With a speech therapist, Sharp used drawing as a means to develop his language. At the age of 11, Sharp invented Laser Beak Man, a superhero cartoon character that now appears on a series of birthday cards and as the main mascot for the Hands on Art Children's Art Gallery at Southbank, Brisbane, Australia. The restrictions of autism prevented him from forming friendships, but through his artwork, Sharp shows his personality, intelligence, and sense of humour.

… http://www.vsartsfestival.org/participants/artistdetail.cfm?artistid=311&artid=267&CatID=1

A4 Contacts

Update team (newsletter)
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Treasurer (donations)
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Awareness Event
Awarenessevent@a4.org.au

A4 Convenor, Bob Buckley
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Profile

Our June Profile is on Joshua Hackett. Joshua is the son of Sheriden and Will Hackett and big brother to sister Hailey. Joshua's biggest claim to fame apart from being a wonderful child is being the inspiration behind Penny Hackett's (his grandmother) idea of the Pin a Pollie Campaign.

NAME Joshua Paul Hackett

BORN 10th February, 1998

LIVES Melbourne

FAMILY Mother Sheriden, Father Will and Sister Hailey

LISTENING The Wiggles, High 5 and Guy Sebastian

READING his Walt Disney books, mainly Toy Story

RELAXING watching DVD's

EATING Nutri-Grain

LIKES Cars, motorbikes, music and Buzz Lightyear

DISLIKES Loud noises, yelling, eggs and porridge

IDEAL WEEKEND having a boys day with dad watching car racing and playing Xbox

LAST HOLIDAY Echuca to see granny and granddad

NEXT HOLIDAY Echuca to see granny and granddad for school holidays